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HEART OF A LION

A Story of God's Grace and a Family's Hope

Derek and John Paul George



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Prologue

I have lost count of the number of days that my wife Annette and I have stayed within the confines of this solemn environment. For us, time stands still. We are riding an emotional roller coaster, bouncing between hope and despair.

It is the end of June, but our daily routine hasn't changed since the birth of our son, John Paul, on June 4. Like most new parents, we remain vigilant at his bedside, but unlike most, we are praying, hoping, and waiting for any signs of improvement.

Our son's cardiologist, Dr. Renar, a woman in her late thirties, approaches us. "Go home," she says. "Get a good night's sleep so you'll be refreshed when John Paul wakes up."

These are the words of encouragement given to us by a doctor or nurse every day. The answer is always the same: "I can't leave because something might go wrong and I won't be around." But tonight, Dr. Renar is persistent. John Paul's condition is stable. I take her advice this time, still apprehensive about my son.

As I start to leave, I realize I'm not sure how to get out of the hospital. The building has become home. Annette and I have been maintaining a 24/7 vigil by our son. We walk hand in hand as we make our way to the bright-red exit sign, but the closer I get to the door the heavier my steps become. I feel guilty for leaving without my son in my arms.

Once home, the first thing that catches my attention is a car seat, the only baby purchase we made. Annette can't bear to look at the car seat. She avoids it and walks into the bedroom. I stand and stare. I envision buckling John Paul in for his first car ride.

We aren't able to sleep for long. Around midnight, the sound of a ringing phone pierces through the darkness. At the echo of the first ring, my stomach churns. The voice on the other end confirms my worst fear: John Paul has taken a turn for the worse. I don't remember getting dressed, but once behind the wheel of my car the adrenaline takes over. I whiz through every stop light and stop sign, flashing hazard lights. The car won't go fast enough.

We finally screech into a parking space and make a mad dash for the door. As soon as the florescent lights and hospital smells hit, the reality sets in. This may be the last time I see my son. We are in a race against time. Annette and I enter the pediatric intensive care unit (PICU). Doctors and nurses surround John Paul's tiny crib. Dr. Renar sees and approaches us; the look on her face says it all.

"John Paul's saturations are dropping fast. His brain and body are being starved for air. It is doubtful his heart will withstand the pressure." She states what no parent wants to hear, "John Paul only has a 1 percent chance of surviving."

Annette's body goes limp. I pull her toward me, trying to stay strong, but I feel I am at the end of my rope. *Why this innocent little boy? Why is he suffering like this? Is this how it's going to end? Is a parent's worst nightmare really happening to me?*

Chapter 1

I was born in Benoni, South Africa, which is just twenty minutes outside of Johannesburg. The tropical climate is similar to south Florida, with the exception of it being a little cooler in the winter. The city has many tree-lined streets, parks, and numerous lakes, which is why it is called the City of Lakes. I grew up in a community known as Benoni Small Farms. Although the name implies I lived on a farm, I didn't. Actually, it was just a home in the country with acres of land but no livestock. There was plenty of room for my sister, brothers, and me to roam and have fun. When I was older, we moved to a quiet neighborhood in Benoni.

My parents have always been very devoted to their Catholic faith, which set a precedent for my brothers, my sister, and me. We all attended Mass regularly, and this foundation of my faith laid the groundwork for the things I stand for in my adult life: faith, family, respect, and determination. No matter the challenges, twists, or turns, I keep my focus on God and my faith, knowing that will lead me through.

One of my earliest memories as a child was of my brother Gary and his sickness. When Gary was born, he was very ill and spent a long time in the hospital. It was hard on my mom and dad trying to keep the household functioning while also tending to my sister and me. My mom and I traveled daily from Benoni to the hospital in Johannesburg. Children weren't allowed in the hospital, so I would have to stay in the car. There I waited patiently and always prayed for good news.

My brother did eventually get to come home, but he struggled for a big part of his childhood, especially during school. People would often pick on him. My parents taught me to watch out for my younger brother and to step in to avert the teasing, so that's exactly what I did. Gary made it

through these obstacles too, and later in life even realized his calling to become a Catholic priest.

My calling was harder to distinguish. Tennis dominated my sports life and actually paved the way to my future. Before I could pursue those future plans, however, I had to serve two years in the South African Defense Force, which was mandatory after graduation from high school. In the army I became a physical training instructor, or PTI. As a PTI, I was in charge of the total fitness of the troops, which included mental, emotional, social, and physical elements. At the time, I regretted having to give away those two years of my life. It was only after the birth of my son that I realized how valuable the skills I learned as a PTI would be in helping John Paul overcome complications.

After completion of my mandatory service, I resumed tennis full-time and I was granted a full scholarship to Campbell University in North Carolina. That's where the interesting part of my future commenced.

It was summer when I met Annette in the school cafeteria. It was one of the first days of the semester. She was attending summer school to finish the one course she needed for graduation. I saw her eating supper with her friend, and my eyes remained fixed on her. She noticed my stare and sarcastically asked if I would like to take a picture, which would last longer, or come and have a seat. Not used to the American lingo of sarcasm, I truly thought she was inviting me over to talk with her. We often laugh about the entire scenario now. She couldn't believe I actually came over, but she was glad I did.

From Annette

Like Derek, I too was raised with God and faith at the forefront of my life. Derek was brought up as a Catholic, however, whereas I was brought up as a Southern Baptist. My dad was a minister, so I was the preacher's kid, otherwise known as the PK.

There are many misconceptions about being a Southern Baptist, as well as about being a PK. We were an ordinary family, though, even if having a

dad who was a minister meant we didn't have an "ordinary" life. We had a good life. My dad didn't enter the ministry for the money. He entered it for the love of God and the people he served.

From the time I was born to the time I graduated from college, we moved six times. All the moves were within the state of North Carolina. We trekked the entire state from near the coast to the mountains. During our first year in the mountains, it snowed and snowed and snowed. I loved every minute of it. I remember getting out of school before Christmas because of the snow and not going back until the end of January. Of course, we paid for all those vacation days when we attended school until the end of June.

We were always a happy family, but when I was in the second grade my sister, who was about eighteen at the time, began to have difficulty walking. Debbie's gait became unsteady and was slowly getting worse. My parents enlisted the help of local doctors, but they were unable to provide a diagnosis. My parents then took Debbie to the North Carolina Baptist Hospital where her illness was finally diagnosed. A rare disease called Friedreich's ataxia, which only affects one out of every 50,000 people in the United States, was taking over her body. The prognosis wasn't good. Eventually, my sister would lose her ability to walk, talk, eat, and care for herself. All she would be left with was her mind, which would remain alert and intact. Her life expectancy was a mere twenty-eight years.

After that we moved again, only to have another life-altering event take place. After two years away at college, my brother came home for good. Frightening symptoms began to appear in Barry just like those seen in Debbie. My parents took him to Debbie's doctors, who confirmed our family's worst nightmare. Barry also had Friedreich's ataxia.

Two out of the three children in our family were already diagnosed with this rare, debilitating, and fatal disease, and I had not reached the age of onset. At the time I didn't think about it, but I am sure my parents held their breath as I approached my late teen years.

For all the sickness we struggled through daily, we were still a close-knit and happy family. My parent's compassionate attitude, perseverance, and fortitude taught me a lot about dealing with others. When taking Debbie and Barry out in public, although the majority of people were empathic,

there were those who lacked compassion and gave insensitive stares or made hurtful comments. The composure my parents displayed during these times taught me an invaluable lesson about empathy and respect. Mom and dad accepted the grace God gave them and put their children first, displaying unwavering love. I didn't know it then, but their example of faith, kindness, and unconditional love became the cornerstone in my life, especially after the birth of my son.

The first time I saw Derek I was standing outside at a pay phone talking to my mom. I noticed this nice-looking guy walking by, and I remarked to my mom: "Oh, there goes that good-looking guy from South Africa."

She laughed and said, "Annette, you think maybe you can find someone on this continent?"

Little did I know that the good-looking guy strolling across the campus would be the love of my life, but I'm sure my mom had an inkling.

Our first "real date" was on a Saturday evening. We decided that we would go to Mass, grab a bite to eat, and see a movie. I was a bit nervous, because Annette said she had never been to a Catholic church and didn't know much about the religion. It wasn't just our religions that were dissimilar. We were also from two separate continents, which added cultural differences to the mix of our relationship. As different as our backgrounds were, however, our faith and belief in the importance of family were the same.

One of the first things I noticed about Annette was her laid-back southern nature coupled with her knack to say what was on her mind. In contrast, there's probably not a laid-back bone in my body, as I am very motivated. Although I'm typically a straight shooter, I also tend to be reserved. As our bond became deeper, we discovered that our differences seemed to complement each other. We remained concerned, however, that our religious differences might become a problem.

We eventually talked about our religions and, although different in some ways, we found that we shared the same core beliefs. We knew that the faith-based backgrounds our families had instilled in us would prove

beneficial in our journey together. I didn't want to let Annette go, and we didn't want our relationship to end because of religion. She told me to remain positive. We would cross that bridge when we got to it.

Our relationship flourished. We began to talk about marriage. The issue of religion became a moot point as Annette decided to convert to Catholicism. She has often said the choice was easy for her, because not only did she love me but she also loved the structure of the Church and the beauty of receiving the Eucharist.

Seven months after we met, I proposed to her. Eight months later, we were married in a small Catholic church. My family wasn't able to travel to the States for the wedding, so we decided to keep it simple.

It's amazing that despite all of our differences we were united. We were united because, although our faiths were different in practice, both Annette and I had been brought up with a strong belief in God, faith, and family. Such things transcend cultural differences. As it turned out, it was our faith that would get us through all the obstacles we would have to face together.

Chapter 2

Annette and I knew that we would eventually start a family. Eight years into our marriage and no children, however, stirs up questions from family and friends as to when “the time would be right.” We dodge the question as often as we can. It isn’t that we’re trying to hold on to our carefree lifestyle, but that in the back of our minds we’re worried about passing on the Friedreich’s ataxia that so negatively changed the lives of Annette’s brother and sister.

Although the doctors assure us the possibility is low, we are reminded each day that there is still that slim chance, as we watch her sister and brother’s conditions deteriorate. Eventually we decide to go to the hospital where Annette’s sister and brother were treated to receive genetic counseling.

The testing is extensive, but the results give good news. In order for our child to inherit the disease, we would both have to carry it. Finally, we are able to think about having a child without fear of a genetic disease.

It is October when we find out that we are really going to be parents. It’s hard to explain our feelings of being blessed, grateful, excited, anxious, and nervous, which are all rolled into one big emotion. We share the remarkable news with our families, and the excitement begins to flow. Finally, those inquiries would receive an answer! The popular response after hearing our exciting news: “You have no idea how your life is going to change!”

We were going to find out. It was definitely God’s timing. He knew now was the right time for us. We had our entire family surrounding us, and we were going to need them.

Chapter 3

It is January 3, 1994, and there is nothing but excitement in the room. I watch the technician initiate our first sonogram. We talk about the Christmas just celebrated and how happy our families are in anticipating our new arrival. Suddenly the small talk ceases. The technician pauses. She looks closer at the monitor.

So we ask, “Is everything OK?”

The technician keeps her eyes on the monitor: “I’m sorry, I’m not allowed to discuss the sonogram. A report will be sent to your doctor, and he’ll be in touch.”

The thrill of the moment slips away, and fear enters. We leave the hospital wondering what might be wrong.

It isn’t until lunch time the next day that we get the news. I have an urge to go visit Annette. I can’t explain it. It just feels like she needs me. As soon as I exit the elevator, I hear hysterical sobs. The closer I get to Annette’s office the louder her crying becomes. I reach the door and freeze. Her body is slouched over in a chair, her head rests in her hands, and her body is shaking uncontrollably. Her friend Margaret stands by her side and tries to console her.

So I ask, “What’s wrong?”

Annette throws herself into my arms at the sound of my voice. She buries her head in my chest. Slowly she looks up, tears streaming down her cheeks: “Dr. Donner just called. He said something’s wrong with the baby’s heart. The baby will need a pacemaker at birth.”

I was shocked by the way we’d gotten the news, over the phone while Annette was alone at work. We were totally caught off guard, not prepared like we would have been if we were in the hospital or the doctor’s office. The doctor couldn’t give us an official diagnosis but did refer us to a specialist.

Until we were able to talk to the specialist we'd be in the dark, not knowing what was wrong or how to care for our child.

It's amazing how, when faced with adversity, the human mind kicks into overdrive and reinstates some form of sanity. We begin to rationalize: *Maybe the technician made a mistake. Besides, the doctor would have called us into his office if it were serious. Maybe we're just overreacting.* Until we know for sure, our emotions fluctuate from worst-case to best-case scenarios.

When we do finally meet with the specialist, Dr. Vega, we aren't sure what to expect. He enters the exam room in green scrubs and a white jacket. He isn't alone. An entire crew of residents, clad in the same scrubs and jackets, follow him in. Suddenly, I feel like Annette and our unborn child are on display. I grab her hand and squeeze it tightly.

Introductions are brief. Just minutes later the scan begins. Dr. Vega studies the screen, pointing to various areas as the residents lean in to also examine the screen. This continues for some time until he finally turns his gaze on us: "Did Dr. Donner explain your baby's situation?"

"He told my wife something was wrong with the baby's heart," I respond quickly, "and a pacemaker would probably be needed."

He clears his throat before adding: "It's very serious. There is no positive news to give you. Your baby has a rare condition called hypoplastic left heart syndrome. The left side of your baby's heart is dead." He pauses, and then says, "The baby is fine in the womb, but once born he or she will die."

Did he just say die? What happened to the pacemaker?

"A pacemaker won't help," Dr. Vega continues. "The only way your baby will survive is with a heart transplant, and even that is a long shot."

My mind reels. The only life our baby is going to have is in the womb....

After that, Dr. Vega introduces Annette and me to Dr. Penski from pediatric cardiology and we follow him to his office. We sit across the desk from the doctor in a state of shock. I keep looking at Annette. Weeks before she glowed with happiness. I can't help but wonder how she will endure this ordeal. The maternal bond is already there.

I think about the surprise baby shower the ladies at her office have planned. This celebration of a new beginning will have be canceled. We'll have to stop decorating the nursery. The house will stay the same. There will be no reminders of what could have been.

Annette and I had gone through all kinds of genetic testing to be sure we weren't carriers of the illness her brother and sister had. We tried to plan, to give our child the best life we could, but something totally different happened. The heart, the most vital of parts, had not formed properly. How could we have planned for this? How will we endure it?

Side by side, hand in hand, Annette and I listen. We nod to acknowledge the doctor's words, but the news really isn't sinking in.

"Is there any hope for survival?" I finally ask.

The doctor shakes his head. "This condition is almost always fatal," he explains. "Without a sonogram this disease can go undetected. At birth, a hypoplastic baby looks no different from any other. Many times mother and baby are released from the hospital. A few days later the baby dies at home because the hole allowing blood flow closes up. We will do everything we can, but..."

Annette starts to cry. I am emotional too, but I try to stay strong for her.

"It's still early enough in the pregnancy," he adds. "You are within your rights to have an abortion."

Annette collects herself. Her words reassure me and ignite hope: "Abortion is not an option. If my child only has nine months to live, then it will be a happy nine months. We will let God decide his or her fate."

Annette's decision leaves no room for argument, but there is still a definite struggle going on between our faith and medical opinion. The doctors are making their recommendations and determining the outcome of our child's life based on the evidence before them. Naturally, their words will linger in our minds, but our faith asks us to think outside those boundaries. "All things are possible for God" (Mark 10:27), even if that's not a factor in the doctor's diagnosis.

We choose faith, not fate. Annette's words set the precedent for our family moving forward, and we move forward knowing the consequences. Our child will live in the womb without a problem, but once born there would be no guarantees. The odds were not in our favor, but we would still give our child that chance and Annette would carry the pregnancy to term.

Our faith proclaims the sanctity of life. That teaching, along with faith, grace, and prayer, would be the cornerstone of our foundation during this time.

Who were we to determine our child's destiny? That power wasn't in our hands—it belongs to God—and we were going to place our trust in him. After that, sticking to our decision would be easy.

The rest of the journey will be filled with obstacles. We know none of that will be easy, and just like today, every other day will be filled with emotions. Today, though, we rally and stand firm in our trust in God and the prayers going out to him for us.