

My Heart

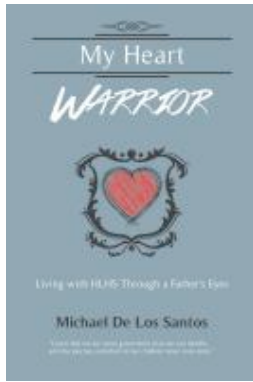
WARRIOR



Living with HLHS Through a Father's Eyes

Michael De Los Santos

"Learn that we are never given more than we can handle,
and the journey on behalf of our children never truly ends."



This is the story of the life and legacy of Aaron De Los Santos through his father's eyes. Discover the incredible journey his family experienced and the enduring lessons he left behind. Whether you or someone you know is experiencing heartache and tragedy, find inspiration from the will to live of an infant. Learn that we are never given more than we can handle, and the journey on behalf of our children never truly ends.

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First Edition

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When I think about telling the story of my heart warrior, Aaron De Los Santos, I must go back to the beginning.

The story of Aaron begins in 2011, but the back story can be traced even further. My wife Gloria and I had a turbulent end to 2010. From the outside, that may come as a shock. We did a decent job of keeping our issues in house, without external drama. I am not going to go into the details of the situation but will say that we considered separating that December.

2011 got off to a better start, and we began to work out our differences, as many couples do. We decided against counseling and began to work on our issues together. We made a commitment to open and honest communications with each other. We knew it would be a rough road ahead, but well worth it.

During our time of healing, we discussed having more children. Gloria was still interested in trying for a boy; I was not in full agreement with this. Part of me was still angry about what we'd been through, while the other part just didn't want to go through the baby process again. My heart was set on adopting a son from the Dominican Republic in a few years. Gloria was supportive of the idea, but I could tell it was not her first choice.

The year moved along, and we had our good and bad days. In March, Gloria told me she was pregnant. It should have been a happy day, but I felt unhappy about the news. When she first called and told me, I said "ok" and hung up. The rest of the day at work, feelings of betrayal stirred inside me. When I got home that evening, I was no longer

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shocked and was rather upset. I lashed out, and made some hurtful accusations.

The accusations were way out of line and in no way accurate. Over the course of that day, I allowed myself to be convinced they had to be true. The next few days were not pleasant ones. I couldn't blame Gloria for how she was feeling, or for the tension that was in our home. It took several days for me to do the right thing and apologize for what I'd said and ask for forgiveness. Given what had happened at the end of 2010, only made these few days more difficult.

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As Gloria forgave me for what I said, we began to slowly move forward. I accepted that my adoption plan was not happening, and began to get excited about the pregnancy. One of my biggest oppositions to trying again was the possibility of having another daughter. My life plan always included two kids, one son and one daughter. Since Gloria already had Taylor coming into our marriage, my plan had been adjusted. I only needed to produce one child to complete that portion of my life plan. However, my first born was not a boy. Instead, we had been blessed with a beautiful daughter, Jordyn Michelle.

Gloria and I were making serious headway with our difficulties, our jobs were going well, and we were moving toward buying a house. Life was in a pretty good place. We began to discuss potential names for both a boy and a girl. Everything was built toward the day we would find out the sex of the baby. I came to every ultrasound, always looking for signs of a boy. We also made the decision to pursue a home purchase, and so there was plenty of excitement for us.

The kids kept us busy as well. Taylor was finishing up the first grade, and was playing on her first baseball team. Jordyn was approaching two years of age, and had us on our toes constantly. It was easy for me to get excited about adding a son to this mix. All of my dreams at night during this time were about having a son.

We put the finishing touches on our savings plan for the home purchase and had begun to look at potential lenders. As a closet real estate junkie, I had already been looking at homes for sale in our

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comfort price range. Eager to get moving on that process, we attended some workshops and set some initial meetings with lenders.

After we narrowed our choices to two lenders, we set up some follow up meetings. One of the follow up meetings was set for June 16th. This was a significant day for us. Not only was it the day after my 27th birthday, but it was also the day after we would find out the sex of the baby. It was to make for an exciting two days.

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June 15, 2011 should have been a great day, and not just because it was my 27th birthday. This was the day that we would find out if we were having a boy or a girl. We were pretty confident it would be the news we wanted. When Gloria was pregnant with Jordyn, the only name we could agree on was for a girl. So when the news came that we were having a girl it came as no surprise.

This time around, the only name we could agree on was for a boy. So we were pretty certain that we were going to be having a boy. It wasn't easy coming up with a boy's name either. We both had very different ideas. After much convincing, I was able to get Gloria to come to my side on the name. Honestly, I am not sure how I did it, but one day she just agreed. One thing I learned from being married is not to fight the victories, so I never asked what changed her mind. I just ran with it, no questions asked.

Those who know me know that baseball and football are my two favorite sports, and that the Atlanta Braves and the Washington Redskins are my teams. So I needed to be able to work the names of my favorite Braves and Redskins players into a name for my son. My favorite Braves player was Hank Aaron. Aaron is a good strong name that I have always liked, so Aaron was an easy choice for a first name. The middle name was a challenge. My two favorite 'skins of all time are Darrell Green and Sean Taylor. Somehow I was going to need a way to combine their names. I figured the best way to combine their names was DaSean. Some of the Eagles fans in my family tried to make the connection to Desean Jackson, the Eagle's receiver, but there is a distinct spelling difference. So we had our name; Aaron DaSean De Los Santos.

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Armed with this knowledge, we went to our appointment at the Duke Prenatal Clinic. It seemed the wait in the lobby took longer than usual, but I suspect I was just anxious. When we finally went back, I wanted to hear nothing else. I know medical professionals have lots of things to look at, but I didn't care about those. The sex was all I cared about. Finally, the nurse asked, "So do you want to know the sex?" "Hell Yeah," is what I said in my head. In reality, I simply said yes while nodding my head emphatically.

"You're having a boy." When the nurse said those magical words, tears of joy streamed down my face. I love my daughter and stepdaughter, but I had always wanted a son and had finally heard those words. As is customary after the ultrasound the nurse left while a doctor in another room reviewed the images for any issue before coming in to talk to us. It was at this point that we started to get a sense that something was wrong.

It usually took no longer than ten minutes for someone to come back in and talk to us. We were approaching thirty minutes, and our happy chatter turned into an ugly silence. After thirty-five minutes, the doctor arrived, and we knew the news couldn't be good.

When the doctor came into the room, she wasn't smiling. My heart began to beat extremely fast. I felt as if I was riding a roller coaster and inching slowly toward a big drop. My heart began to pound because I knew something was wrong. Then she delivered the news. The images showed some irregular blood flow, and it appeared the heart had not fully developed on the left side. She was pretty sure of the diagnosis, but wanted us to go to Duke Children's Hospital and their pediatric cardiology unit for clarification.

She talked some more after that, and escorted us to a different room. I don't remember anything else she said that afternoon. Her mouth moved, but I wasn't able to process anything she said. My heart was in my throat. We had hit the drop on the roller coaster and all my breath was gone. I was finally having a son, but his heart had not developed. This was somehow the best and worst birthday I had ever had. I wasn't sure how to handle it.

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After the appointment with Duke had been set, we left with a cold feeling. We didn't know what to do or what to say to each other; we were just lost. Between the two of us, there were a lot of tears shed. We ultimately got ourselves together and talked about being strong to get through this. We knew, regardless of what happened, we needed to be strong for each other and the girls.

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We decided to proceed as if nothing drastic had happened. A few close friends and some family had been told of the news, but until we had a confirmation and had done our research we kept the news from the general public.

We also made the decision to continue on the path towards homeownership for now. The day after we got the news, we had a follow up meeting with a potential lender and began the process of gathering everything we would need to continue. We told the girls that they were having a brother, but left out all the details of his possible condition. We figured the less they knew the better. However, the truth was that we had no idea how to tell them.

No matter how much research I did or how often I spoke to those close to me, I was still in denial. I thought the diagnosis couldn't be true. Perhaps the ultrasound wasn't accurate or they'd read it incorrectly. The information I was gathering was scary and pushed me further into denial. I felt angry. Part of me wanted to blame Gloria for what was happening. In hindsight, I should have been more supportive of Gloria during this time. It was definitely a period of going at it alone for both of us. We wanted to deal with it in our own way.

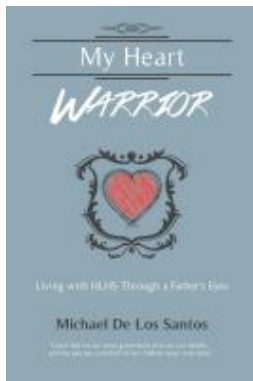
When the time came for the follow up appointment, there was a lot of nervous energy between the two of us. We had done our research and were as ready as we could be to hear the news. After the heart echo, the doctors confirmed Aaron had Hypoplastic Left Heart Syndrome. This is a rare heart defect in which the left side of the heart never develops. In Aaron, only the right side of his heart developed, which

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explained why the blood flow had appeared off during the previous ultrasound.

I was crushed all over again. No longer could I deny what was happening. I can't speak for Gloria, but for me this confirmation was not as devastating as the original news. I guess I had already blown through that emotion, and was eager to learn our next steps. The first question was how did this happen? Was it something we had or hadn't done correctly? The doctors were quick to assure us that this was not of our doing. We were told there was no known cause for the defect in Aaron's heart and that we shouldn't question ourselves. That was easier said than done, and we did spend some time being really hard on ourselves.

Eventually we got through that and began to focus on what was next. We knew that there would be regular visits to Duke Children's Hospital for heart echoes to monitor his progress. Now that we knew the diagnosis, we tried to learn as much as we could about it. We hoped the worst of the bad news was behind us, and we focused on moving forward.



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