

# My Story

*Our Mission* The Hemophilia Federation of America (HFA) is a national nonprofit organization that assists and advocates for the bleeding disorders community.



## By Rick, Jessie's Dad

My son Jesse was born on Valentine's Day in 2001. He is now 4 years old and has severe hemophilia. It is hard to believe the amount of emotions that have transpired in the short period since his birth. Life leads us down many paths. The path of fatherhood is filled with untold joys, unbelievable heartbreak, and constant education and expectations.

Fatherhood begins from the time of conception. In my case, the months leading up to Jesse's birth were times of doubt and anxiety. In my circle of friends, I was the crazy one. I was the one who shaved my head, rode a Harley, and had the majority of my upper body covered with tattoos. What did I have to offer a child? I felt my physical appearance would be a deficit to any child. What kind of father would I be? Could I even be a father? To be quite blunt, I was scared to death. Who was I kidding? Then to top it off, we learned we would have a son and even better, he was going to have hemophilia. Surely God had a good laugh when he chose me for such a task. Still, life moves on and my son was born.

Jesse came into this world as the result of a scheduled C-section in order to avoid any complications that his hemophilia could cause during natural childbirth. They pulled him from my wife's belly kicking and screaming. I saw him and cried uncontrollably. Through the tears I realized that my fears and doubts were gone. It was now crystal clear I would be the best father I could. Instinctively, I knew that I would love this child, fight for him, and do whatever was necessary to ensure his well being.

The first two nights that Jesse was home, I rested on the floor at the foot of his bassinette. I hardly slept at all. I was constantly checking on him by putting my hand on his chest to make sure that he was breathing. So began six months of pure joy. Each day fresh. I was amazed to see how quickly Jesse changed. Each day he learned something new. And so did I. Most nights I would rock him to sleep while singing to CD's that played in the background. Life has few perfect moments but these were some of my best. Then at 6 months of age, the specter of hemophilia raised its head.

I guess we always knew the day would come, but nothing can fully prepare you for your child's first bleed. It was such a subtle thing. I was giving Jesse his morning bottle when I noticed he would not hold it like he normally did. Then BOOM! It hit me. I woke my wife. It became clear that something was wrong. Yet to the untrained eye we could see no visible signs of a bleed. Still we called his doctor and prepared to go to the hospital. In the short time that it took to get ready, Jesse's pinky and adjoining finger slowly curled up and would not straighten back out. After a brief exam at the hospital, it was confirmed. Jesse would need his first infusion. After several attempts at hands, arms, and feet, it was determined that the best choice was infusing through the scalp. They were going



*For additional stories or to share yours, contact HFA*

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to stick a needle in my son's head. My wife and I lost it. I could hear my wife's frightened screams as she ran out the door and down the hallway. I was sobbing and out of my mind. Unfortunately it had to be done. And I had to stay. I have withstood much physical pain. Nothing ever hurt me more than to watch them stick that butterfly into my son's head. In a heartbeat, my 6 months of joy were replaced with the harsh reality of hemophilia.

Over the next 18 months, it was a scene that was repeated on a regular basis. A bleed would occur. Off to the hospital we would go. My wife would leave the room and I would stay with our son while they infused him. Unlike the first time, I no longer cried. I had to be strong for my son. It worked. Over time he became comfortable with infusions. In a strange way, it has given us a bond that can never be broken. It got to a point where his infusions could only be done if he was sitting in my lap. I was his safety net. As long as dad was there, it would be okay. Although the infusions became easier, the 45-minute drive to the hospital and the constant fights with ER personnel didn't. So we went to home nursing and having Jesse infused in his own environment.

Using home health care gave us more control over Jesse's disorder. It also changed the dynamics in our family. My wife, now a stay at home mom, finally was able to participate in Jesse's infusions. The burden of responsibility slowly shifted from me to her. Gradually and almost unnoticeably, I was left out of Jesse's medical care. We still spent a lot of time together playing and exploring the world. Every place that we took him, he was like a sponge absorbing all the things that I would tell him about his world and environment. I became complacent with his disorder and focused my attentions on just being dad. That would soon change.

My wife from the beginning had been involved with the hemophilia community. I, on the other hand, shunned it seeing no purpose. I was a good father to Jesse and felt that I could handle his disorder on my own terms.

Then one day it was determined that I was the perfect candidate for a Hemophilia Federation of America program called "Dads in Action". Reluctantly I was shipped off to Lafayette, LA., to be trained as a facilitator for the program.

Before leaving I had predetermined that I would gain nothing from my trip. I decided I would be courteous and affable at the sessions and come back home no worse for wear. Boy! Was I wrong! Almost immediately after our first session began, I could see that I would be affected and changed by this experience. As I listened and talked with the other fathers, I realized that the term "Blood Brothers" not only pertained to hemophiliac's themselves but also to us as fathers of affected children. As things progressed, I realized that I had placed myself on an island and that there was a purpose to being involved. Each of us as fathers brought shared and unique experiences that helped each of us become more complete. As our discussions continued, I soon discovered that I had failed my son for the mere fact that I did not know how to infuse him. This was something that my wife had been doing for over a year.

I have taken away from my experience at Dads what I needed; the motivation to become more responsible for my son's medical needs. I made a promise to my "brothers" that within 6 months I would be infusing my child. It took me only 3 months. A promise has been fulfilled.



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As of today, I am still infusing my son. Probably not as often as I should, but I am a work in progress. I have become more involved in our community and only regret that living life does not allow more dedication to my son's cause. I have determined that each of us should do what we can, when we can to support the bleeding disorders community. If each of us did just a small part, in the end the whole would be much stronger. I am writing this article in hopes that it can educate and motivate some other father to become what his child needs. It is a part of my commitment to "Dads in Action" and my moral responsibility to do so.

Lesson learned: Don't be afraid to expose your emotions to others who may benefit from your experiences. 🩸

