Dylan Has Changed My Life Forever

By Brian Manning

On March 28, 2003, my heart actually stopped for a few seconds and then my life was forever changed as I learned about Tay–Sachs Disease. Previously that day, I had spent a few hours in an ophthalmologist's office trying to figure out what was wrong with my son. A picture of Dylan's eye was taken and the cherry red spots had been revealed. The doctor then threw out the words, "Tay–Sachs Disease." He wasn't positive; he really didn't know what Tay–Sachs was and neither did I.

That afternoon, I went back to work to catch up before the weekend, and as I was about to walk out the door, I decided to do a little research on the Internet. It was at that moment when I read about this nightmare disease. I remember saying to myself, "No way, not Dylan. This has to be wrong." But as I kept reading about all of the symptoms for Tay–Sachs, everything described, matched all of Dylan's symptoms, including the cherry red–spots, the developmental delay, and the startle response. I took Dylan for blood work on Monday, March 31, 2003, and he was officially diagnosed the next week.

My first thoughts were, "Why Dylan, why us, why me?" I didn't want my son to die. This was going to be the most difficult road I had ever traveled, and even a more difficult one for Dylan. At that instant, I wanted to switch places with him. There were too many things he was going to miss out on and that was unfair.

My outlook on life, work and play has completely changed. Dylan has made me a better father, husband and person in such a short time. He has taught me the true meaning of unconditional love. Without saying a single word, he helped me to realize what the most important things in life are. There will always be work for me to do. Dylan might not always be there. So if work isn't there tomorrow, I can always find another job. I can't find another Dylan, as he's irreplaceable.

Going to work each day is the most difficult part of my job; I would rather spend all of my time at home with Dylan. But, each day, I realize what my responsibilities are as a father, husband and provider. At one point in time, money and my career were important things in my life, but not anymore. My job does provide the benefits and salary needed to help my family survive, so I realize that this is one responsibility I must maintain. Luckily, my employer is flexible with my time off, so my job allows me to spend more time with Dylan, but I try not to take advantage of my good situation.

Prior to Dylan's diagnosis, I was very involved in the community. Since college, coaching and refereeing basketball games was something I did 3 to 4 times per week. When Dylan was born, I dreamt of the opportunity to coach him. I treasured the thought of one day being able to shoot baskets with him in our driveway, or throw a baseball with him in our backyard. I imagined being a spectator at one of his games, where he was the one shooting that last second shot or hitting that game–winning hit. These are all thoughts you have when your first son is born. These are all thoughts I was having as I coached and refereed other children. Picturing Dylan doing all these things was easy for me, because even prior to his diagnosis, I knew he was something special.

Since Dylan's diagnosis, I have been given the opportunity to meet people I would not have met otherwise. Complete strangers have been introduced through Dylan and his foundation and I am always amazed at the type of people who extend themselves and want to give a helping hand.

At the same time, relationships with many people have changed and become strained over the last couple of years. My closest friends are more distant. Most of them just don't understand what we are going through, and sometimes, they don't know what to say or how to approach me. They don't understand that I would rather spend time with Dylan and that he is my favorite pastime now.

My marriage has remained very

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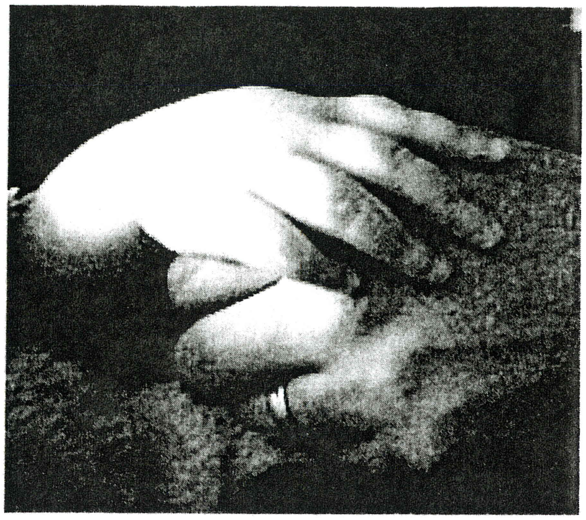

strong; the support my wife and I give each other is unspeakable. I would be lying if I said that we didn't have any rough times, but that is what makes us stronger for Dylan. We play off of each other very well. We pick each other up when the other is down. We always pray, for Dylan's sake, that both of us don't have that 'bad day' together on the same day.

My life has basically changed forever because of an enzyme deficiency. I never thought that those words would come out of my mouth. My hero is a 4–year old little boy who cannot speak a word or move a single muscle. And although I am very saddened by the fact that Dylan won't grow up and do all the things that other little boys are supposed to do, he has taught me more about life than anyone I have ever came in contact with. I am very proud to be his father.