



My Daughter Danica

No matter how many years have passed, I remember her birthday as if she were a minute old. There are just no words to describe the everlasting impact such an event has on you mentally and emotionally. Before she was even born, I knew something wasn't right, and I kept asking the doctor to run tests and figure out what was wrong. Of course, they felt I was a fanatic and promptly ignored my concerns. So, when Danica arrived and the doctor didn't sound like he knew what he was talking about, I, as a mother who had innately known something was wrong, decided he was an imbecile and wrote him off. Yes, I had a little bit, okay, a lot of anger and fear going on here. Fortunately, my sanity was saved by my mother, who completely understood and supported me in every way during my life. Without that, I don't know how things might have turned out.

Learning what made Danica different wasn't a relief from not knowing; it just was. Having a name to put on my fears for her future didn't suddenly change my perception of her life; it just made my answers for questions from others a little easier. Shorter. Convenient. What at first made me extremely angry and fearful, now completely enveloped me with an intense sadness. I immediately felt I had to either agree with the diagnosis and accept their prognosis for her future, or deny it and fight for her to be better than what 'they' said she would be.

The first diagnosis for Danica was 'Dandy Walker Syndrome' associated with occipital meningocele. Simply put, it's a neurological disorder that doctors believe manifests in the 5th month of fetal life. The brain has pockets of cerebral fluid called ventricles, and one of them is located in the back of the brain, along the brain stem, and when enlarged, can affect the occipital lobe where the brain processes vision data from the eyes. This particular pocket, the fourth ventricle, became enlarged with cerebral fluid, not allowing it to flow down through the spine as normal. The consequences are numerous, and we were told, it can greatly shorten the life span.





In Danica's case it was suggested she would not live past the age of 12. That statement was certainly always at the back of my mind, but I refused to allow it in front. The fear was simply more than I could deal with. My sadness was overwhelming, which I believe drove my fierce determination to make things okay. I was going to make her better than they said she would be and make her happy even through all the pain she had to endure. At least that was the plan. I had the same question going through my mind: "Why would this happen to an innocent child?" I just couldn't make any sense of it, and it made me angry. I think you can imagine, and many of you know, what can happen when Mama Bear gets angry and protective of her cubs.

My anger led me to search for answers to why, solutions to get her well so she could be 'normal' as most people define normal, and my fear drove me to the brink of insanity. I had to fully cherish each day because I didn't know if I would get another one. As time went on, I discovered that the days I treasured were gifts on how to have unconditional, infinite love, patience, and compassion for another person. How to see their soul and not even realize they walk, or talk, or look different became a reality I didn't even know had happened.

Due to the neurological damage, Danica had lost her sight and only gained some of it back in time. This naturally had a huge effect on our family, learning how to take care of her and teaching her how to grow up with little or no sight. At one point in the earlier part of those years, there was a community program where elderly women volunteered to be grandmothers to handicapped children. The director of the program asked me if it was okay if an African American (I hate that term by the way, we are all just Americans, no matter what color, culture, or continent we came from. I don't call myself an Irish German French English American either.) woman became Danica's volunteer grandmother. My answer was, "Danica can see their soul and knows if they are good. She feels their touch and doesn't care what color their hand is, only how soft their caress is. Of course, she can have any grandmother that is good to her, I don't care what race, culture or continent they are from." This was when I realized how much my daughter had already taught me and how deeply she had touched my heart and my soul. I was now also





seeing with my heart and soul.

Having a handicapped child is hard. Programs to really help her achieve as great a quality of life as possible, especially if your child has a rare condition, are few to none. If their 'condition' doesn't fall into a nice and neat little category, you will be hard pressed to find a group offering services for anything other than the hardcore medical procedures. Danica's condition at the time made her the thirteenth one in the world, and pictures of her soon graced medical textbooks. And don't even get me started on getting medical insurance for her. That is a nightmare all by itself. I found that people outside of what is considered the norm are treated more like objects than humans with emotions and a beating heart. There is so much that so many people, especially medical people, can learn from children with special needs. I hope that happens faster than it has been going so far.

No one talks about the impact a handicapped child has on siblings, a very real and important aspect. It is never even addressed, and I can't speak for the fathers, but the mothers live with guilt forever. I had not done anything wrong to cause her condition that I knew of, and believe me that is a question I will never stop asking myself, but I still felt guilty like it was my fault that my child would never be able to run and play, have a teenage girls sleep over, go to the prom, have a career or a family of her own. And I felt guilty about robbing the other siblings of a normal childhood. There just seemed to be no way to win. No way for things to just be easy. No way to feel like a normal family, and yet I felt blessed to have the honor of raising this beautiful, radiant, joyful little girl. I believed and truly felt I had been specially chosen to raise a handicapped child because it was so hard, not a lot of people could handle it, and I was just stubborn and selfish enough to forge the path I needed for her, for me, and my other children, and not lose myself in the process. The icing on the cake was the honor I felt to call her my daughter. We had a special bond. I could hear her speak inside my head, and I listened. Not a lot of people can say that.





As Danica grew up, I first only saw pity from people because she had difficulties, but then I started to realize the tremendous impact she had on others. Yes, people would still feel sorry for her, that is only natural, but they also felt something that affected them on a deep down to the soul level. It's an invisible pure energy of unconditional, unfathomable love that people receive from her. You don't even realize what is happening until you feel the profound emotions stirring in your heart.

Danica has and continues to touch so many lives. From the people she has touched, some have written poems about her, one of which a friend of mine framed for me. Others have gotten into music therapy, nursing, and social work, just from having known Danica. She makes you happy in spite of yourself. She has a hug when she consents to give you one, that soothes your soul, and she has a lyrical laugh that makes you laugh too when you hear it.

Despite it all, the difficulties, the medical problems, the pain she has suffered, and the incomprehensibly painful headaches she still suffers, she is still a child of pure heart and can be as mischievous as the best of them. Once, I had to help the doctors hold her down while they inserted an IV. I literally laid on top of her and shifted my body in whichever direction she was moving, trying to keep her still. Believe it or not, the doctor asked me to help since six other people couldn't hold her. Yes, she really was that strong. She was kicking her legs, so I slid down to put more weight on her legs, and as soon as I did that, she raised her head and slammed her forehead into my eye, giving me an ugly black eye. I immediately told her she had just clocked me in the eye, and she thought it was extremely funny, laughing hysterically. Her laugh is infectious, and the doctors had to laugh too. To this day, when I remind her of when she gave me a black eye, she repeats the same sidesplitting laugh. And then I have to laugh all over again, thankful for the joys she gives me.

She makes me happy. She makes everyone happy. Through all her pain and arduous daily struggles, she finds joy and infects everyone she comes in contact with. To know Danica is to be blessed in life. I don't believe in coincidences; I believe we are where we are supposed to be to do what we are supposed to do. I am so thankful I





I have been privileged to do with Danica all that I have done.

We used to play games, simple ones that we could do anywhere. Simon says, a high-five count by fives that she would slap my hand five times or however many the number was, a hand pile where you layer your hands and the bottom one pulls out and starts on top again, and many more. We would sing songs that she would sign, or play music or videos, and we would laugh with every game, song, or video every time. When we played the high-five or hand-pile games, she would always wait for a time, and then purposely mess up. For the high-five game, she would do the 5, 10, 15, 20 counts, and then sometimes even to 45 (even though she could do 100 if she wanted to), but somewhere in there, she would always miss the count and then wait to get my reaction. I would proclaim she was cheating and to stop cheating, and she would giggle nonstop, saying "Oh Mama". She loved the reactions and always did something to get them. We loved her giggles, so we always complied.

Danica loved the Chipmunks. I think it was mostly because Alvin got in trouble. After all, you could see her waiting when Dave would start out saying Alvin a few times, and then when he screamed "ALVIN!" she would laugh and laugh. She did the same thing when her siblings, Justin or Alysha, got into trouble.

I am deeply grateful to be able to continue to swirl her infinite love and overpowering joy with others who need it. Danica turned 32 years old in July this year, 2013. That's a far cry from 12. I believe she just isn't done with her mission for others, and I am determined to help her in every way I can. It appears I am very selfish and can't get enough of her beautiful face, heart, and soul.

Her mission for me has rung through to my soul. To have such grace from my daughter, beautiful, joyous soul, Danica, I am completely blessed. No matter when Danica leaves us for higher ground, her imprint will live on in others for a very, very long time. Just ask anyone who knows her, especially her sister and brother.

These days, I am writing children's and young adult stories. It is a passion that deeply moves my soul, a soul that was shaped by the many profound events in my life. People have always told me I need to write my life story because it's something most would have a hard time believing. I just might do that,





but I don't think I am at that point yet. So much more has yet to happen that I will have to include. I am sure that if I ask Danica if I can write about her, she will laugh, her lyrical giggle.... and then I will too.

Today I am updating this story for the third time, but what I write today will be the last. Dearest Danica went to heaven with Jesus today, and in my mind, I saw her holding his hand and skipping and hopping beside him. Danica was born on a Wednesday, July 22, 1981, and left me on a Tuesday, April 5, 2016, 34 years, 9 months, and 14 days later. A time too short but more complete and joyous than I could have ever imagined. My blessings are many.

I was given a gift to love, cherish, laugh, and learn, which many people never get. Her beautiful heart and soul brought more love and joy than I ever knew was possible. Seeing the love and relations between her brother and sister is a constant movie playing different scenes in my mind, and each one makes me smile and my heart sing. She taught them many things as they did her.

The pain of her loss severs a part of my heart, but that is the greatest evidence of the infinite depth of love she created. Even with that pain, the joy of Danica far outweighs the ache of any day. How lucky are we that were granted the time to live with, care for, and learn from a master, the true meaning of life.

As I said earlier, on our journey I found that coincidences are nonexistent because we all meet the right people and passages at just the right time. I witnessed this. I have lived this.

I did ask Danica, by the way, and I will be writing a book about our journey, but it will take me a while. The pain of her going home is still a throbbing one, so it is still hard to write without crying. Danica told me to name the book *Hidden Blessings*. So, I will. How perfect is that?

Love & Many Blessings,

Colleen M Bratley

