

My Daughter Danica

By Colleen Sonntag

No matter how many years have passed, I remember her birthday as if she is minutes old. There just are 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 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 really 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 answer to questions from others a little easier. Shorter. Convenient. And now, what at first just made me extremely angry and fearful, completely deluged me with an intense sadness. I now felt I had to either agree with the diagnosis, 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 which doctors believed manifested in the 5th month of fetal life. The brain has pockets of cerebral fluid called ventricles and one of them is in the back of the brain near the sight or occipital portion. This particular pocket enlarged with cerebral fluid not allowing it to flow down through the spine as normal. The consequences are numerous, and we were told, shorten the life span.

In Danica's case it was suggested she would not live past the age of 12. Of course that statement was 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 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 hap-

pen 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”, and my fear drove me to the brink of sanity. I had to absolutely cherish each day because I didn’t know if I was going to get another one. As time went on I discovered that the days I cherished were gifts of 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.

Due to the neurological damage, Danica had lost her sight, and only gained some of it back. This of course 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 woman became Danica’s grandmother. My answer was, “Danica can see their soul and knows if they are good. She can feel their touch and doesn’t care what color their hand is, only how soft their touch 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 me.

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 or 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 hard core medical procedures. And, don’t even get me started on getting medical insurance for her. That is a nightmare all by itself.

The impact of a handicapped child on siblings is a very real and important aspect, yet it is never even addressed, and I can’t speak for the fathers, but the mothers live with a guilt forever. I had not done anything wrong to cause her condition that I knew of, 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. 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 so blessed at the same time.

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 would feel to be able to call her my daughter.

As Danica grew up I first only saw pity from people that she had difficulties, but then I started to realize the tremendous impact she had on other people. 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 I even have framed, 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 will give you one, that soothes your soul, and she has a lyrical laugh that makes you laugh too when you hear it.

She is a mischievous child in spite of it all. 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. 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 up, 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. To this day, when I remind her of when she gave me a black eye, she laughs hysterically. And then I have to laugh all over again.

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 got to do with Danica all that I have done.

I am deeply grateful to be able to continue to swirl her infinite love and overpowering joy to others who need it. Danica will be 29 years old in July this year 2010. That's a far cry from 12. I believe she just isn't done with her mission for others, and I am going to help her. I hope you will join us too.