

# Joys and Challenges of Being a Parent, When the Parent has VCFS

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Before deciding to have children, my husband and I knew we had challenges that most couples don't have. My husband, Doug Lindsay, knew I had VCFS at the very beginning of our relationship. My diagnosis came when I was just twenty three years old. Doug and I had just started dating that summer, of 1998. I'll never forget learning about my diagnosis, and feeling that the whole world was closing in on me, because I now had a "label" for all of the obstacles I had faced growing up. The diagnosis didn't make sense to me immediately. Luckily, I had my now husband of 10 years, to help me make some sense of it.

I remember coming back from the appointment at Children's Hospital Boston, upset and confused. I thought there was something "wrong," with me, now that I had something called Velo-Cardio-Facial Syndrome. I worried that this amazing person, my now husband, would think I was flawed, not worthy of marriage. Would this diagnosis change how he felt about me? I also wondered: would we be able to have the relationship we wanted, knowing about my diagnosis? Would we be able to have a healthy, VCFS free child/children together?

When I told Doug about the diagnosis, his reaction was the complete opposite of what I expected. I told him frankly and honestly about the diagnosis, uncertain of the outcome. He then hugged me, looked into my eyes and said: "there's nothing wrong with you. You're still the same wonderful person I knew before the diagnosis." I was overwhelmed and, at the same time, overjoyed by his positive

and supportive response. He already knew about my heart condition, and that I had open heart surgery (a VSD repair), at the age of 2. For him to accept me for who I was as a complete person, was something I had rarely experienced.

Thanks to my husbands support, and love, I was able to come to terms with my diagnosis. I have become a stronger, more successful person because I have accepted who I am. When we were ready to start a family, this solid understanding of one another helped us determine the correct path for having children.

We are fortunate to live in the Boston area, where we have some of the best doctors and medical experts in the world. So, we knew that if we did have to seek an alternate path to having children (in-vitro-fertilization, IVF, or pre-genetic diagnosis, PGD), we would be in good hands.

Before deciding how to have children, we met with several doctors. A genetic counselor, IVF/PGD doctors, my cardiologist and reproductive science experts. We had all the testing done, and then some. We were pretty certain we would be conceiving a child through IVF and/or PGD.

It was one meeting with a genetic counselor who changed our whole perspective, and our path changed. She said: "while there may be a 50/50 chance your child will inherit VCFS, or the 22q deletion, there is not a 100% chance". I had not heard that from anyone before, up until that point.

Knowing there was still a 50/50 risk our child could have the deletion, or VCFS, we weren't yet convinced we should conceive naturally. For some reason, however, I felt it was possible for us to have a healthy child, without doing IVF/PGD.

Even though we knew we were now on a risky path, we decided not to have a child through IVF/PGD. I felt that IVF wasn't right for me, personally. I had already been through enough medical problems: a VSD repair at age 2, a scoliosis diagnosis in middle school, which led to me wearing a back brace for two years, and a few other issues. To me, the thought of dealing with injections for IVF was just too much. I had already dealt with more medical issues than most people ever experience. For me, that was enough justification not to conceive a child through IVF/PGD, though I knew it was a risky decision.

Knowing the risky path we chose to go on, we knew we had to be cautious about who we told I was pregnant. It was in 2008 that I learned I was pregnant, and was feeling amazingly healthy, even early on in the pregnancy. We sought the appropriate cardiology team, at Boston Children's hospital, to monitor my heart during the pregnancy. We found an outstanding OBGYN at Brigham and Women's hospital in Boston, and overall, had top notch care. Again, we were/are so blessed to live in a metropolis with such excellent medical care.

My pregnancy was, actually, a very good one, as pregnancies go. Because we had taken a risk by not doing IVF/PGD, we had a CVS test done at 13 weeks. The CVS test was necessary to find out if our baby had the 22q deletion/VCFS. My husband was there when I had the CVS test done, and, thankfully, everything went smoothly. We both will never forget receiving the call from our genetic counselor at Brigham and Women's Hospital. I could tell by the tone of her voice that it was good news. I barely heard her say the baby was healthy, because I was practically in tears already. I had a feeling that our baby was healthy because it was developing so normally. Fortunately, the CVS test confirmed that our baby was healthy, and that it was a healthy baby girl. That was one of the most joyful moments we shared together, that we will never forget.

On Christmas morning, of 2008, I went into labor. Our beautiful baby girl, Alissa Grace Lindsay, was born on Dec. 26<sup>th</sup>, 2008, at Brigham and Women's Hospital, Boston. After a 24 hour labor, she was born via c-section. My husband was the first to meet Alissa, extracting her from my belly, followed by my parents and birth doula after we left the OR. Everyone, including my self, was in awe of this amazingly beautiful baby girl.

Little did my husband and I know that we were suddenly parents. Two years later, it's hard to imagine how we knew what to do after she was born. Even with all the planning during pregnancy, no one told us what to expect after she was born, or how to "be parents." There were sleepless nights, constant feedings from me, since I nursed for eight months, while my husband still had to work, and I had to figure out how to be a Mom.

At the beginning, I was definitely overwhelmed. I had such a wonderful pregnancy, and all of a sudden I was a Mom. This reality hit me after we left the hospital, and I realized that I had to nourish, love and protect our baby girl, without all that extra help we had at the hospital, or knowing how to be a Mom.

Before having Alissa, and becoming a Mom, I had to come to terms with having VCFS, and accepted myself as a person with VCFS. Luckily, or not, my case is considered mild, and most people don't even realize I have it. That alone presents many challenges for me. Because most people think I'm like everyone else, it's more difficult for me to take care of myself. Especially since I became a Mom, it's even more difficult.

As any Mom knows, taking care of yourself becomes a second priority. Your child is your number one priority, not you. This was a challenge for me, as I feel I often stretch myself thin, even before I became a Mom. That's what people

who supposedly have “disabilities,” (honestly, I dislike the word *disabilities*), have to deal with. We want to be just like everyone else, and not have “labels” thrown on our backs.

As a Mom, I have had to figure out who I am as a “normal Mom,” and the “Mom with VCFS.” I feel that I often portray myself, almost too well, as being a “normal Mom,” with no limitations, or different health needs. Only people in my family, and close friends, know the real issues I face.

Some days, if I’m just too exhausted from Alissa not sleeping well, waking up a couple times at night, I will choose to cut back on my activities/obligations, so I can rest, and stay healthy. I am fortunate in that I’m able to work from home. I teach piano, from my home piano studio. So, that is a tremendous help. Still, I have to be careful not to overextend myself. I occasionally forget that I have VCFS, because I can handle day to day life so well. Often, I have to remind myself, and others, that I have to slow down, in order to be the best person, and most importantly, Mom, I can be.

In retrospect, becoming parents was the best decision we ever made. Now that Alissa is a toddler, and gradually becoming less needy of us (especially me), I’m starting to see the light at the end of the tunnel. I’m beginning to appreciate all that is so amazing about her, including how healthy she is. She is developing flawlessly, and impresses us every day with what she can do.

Now that I’m a Mom, of such a beautiful little girl, I feel like I can let her steal the show, and get all the attention she deserves. We’ll do our best to provide her with a wonderful foundation, and will let her take her life wherever she wants to. She certainly has the tools to have a tremendously full life. It’s now her turn to lead us in the right direction, and show us her path. I can’t wait to see how amazing her path will be.

*Knowledge is Hope*

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