

Down Syndrome

Days and Dreams Filled With Promise

By Adrienne Vadell Sturges

Back in October 2002, I was eight months pregnant with my second child. My husband and I had a beautiful, almost 2-year-old daughter, Kaely, who was as eager as we were to meet her new baby brother or sister. I had a relatively uneventful pregnancy, and I was starting to “nest” – big time. With only four weeks left to go, I decided to have a mural painted in Kaely’s “Big Girl Room.” We went with a farm animal theme, and it immediately became my favorite room in our house. Over the next several days, I would visit the room often, both to admire the final results and to daydream about what our new family dynamics would be like once the baby arrived. If the baby was a girl, she and Kaely would wind up sharing this room growing up, just like I shared a room with my younger sister.

Exactly one week later, I started having labor pains. I walked into the hospital at 7:30 on a Saturday morning. By 9:05 a.m., I was holding my beautiful new baby girl. We named her Clare Mairead. I recall thinking that Clare looked a little different than her sister, and she kept doing this funny thing with her tongue – sort of poking it in



Clare’s arrival

Photo courtesy of Jodi Moore

and out of her mouth. She had some trouble latching on when I first tried to breastfeed her, whereas Kaely had no troubles at all. Despite these differences, I never suspected that anything was “wrong.” Clare very much resembled my first daughter. They shared their father’s nose and mouth. In addition, Clare had my straight brown hair and fair complexion and was a healthy seven pounds, three ounces. Not bad for a baby that was a full three weeks early! She was moving all around and looking up at me. My husband and I cried tears of joy. She was perfect. Just perfect.

Receiving the News

A couple of hours later, our lives were forever changed. A team of doctors, nurses and social workers came into my hospital room and told my husband and me that Clare had been moved to the NICU because she appeared to be having some trouble breathing and required oxygen. Panicked, my initial instinct was to ask whether or not she had suffered any brain damage due to the lack of oxygen. The neonatologist fumbled a bit with his words, yet assured me that she had not. However, he went on to

explain that Clare possessed some “unusual physical characteristics.” I was 34 and, to this day I’m not quite sure why, but I blurted, very matter-of-factly, “Down syndrome. You think she has Down syndrome?” He said it was a “possibility.” Later that day, a geneticist confirmed that Clare did indeed have Down syndrome. We also learned that she had two small holes in her heart that would have to be surgically corrected if they did not close on their own.

At the time, my husband and I knew relatively little about Down syndrome. I knew that it was caused by an extra 21st chromosome, and there were certain physical characteristics associated with it. I also assumed that it meant our daughter would be “mentally retarded.”

We were devastated. Everything in my being told me that this would be bad for my family, and I honestly thought that we would never be happy again. Some advice offered by a well-intentioned but ill-informed nurse reinforced this fear.

The night I returned home from the hospital, I recall crouching in the dark, next to Kaely’s crib. I sobbed as quietly as I could, so as not to wake her, and begged her forgiveness for not giving her the sibling I had promised. I couldn’t bring myself to glance up at the mural on the wall, the mural that just a week and a half ago had been the source of such joy for me. It reminded me of all the dreams I

Almost four years later, I remember just how desperate I felt at the time, and I wish the “me” I am today could go back in time and tell the “me” back then just how wrong I was.

Over time, I discovered that my early reactions were more about my own insecurities than they were about Clare or Down syndrome. Once I could finally admit that to myself, I received more in return than I ever could have imagined possible

had for my daughter and her new sibling, dreams that I was now certain would never come true.

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Finding Clare

The first year following Clare's birth was hectic. It was filled with what felt like weekly visits to pediatricians, geneticists, cardiologists, pulmonologists, gastroenterologists, optometrists and audiologists to assess a number of potential medical issues. Beginning when she was 2 weeks old, Clare received county-funded services in our home in the areas of physical, occupational and speech therapy and special instruction. And with all of this as a backdrop, my husband and I were trying to come to terms with Clare's diagnosis and to figure out what role it ultimately would play in our lives and in our family. Most importantly, we were struggling to get past the Down syndrome and simply get to know our daughter.

I now recognize what a significant role my ego played in my early reaction to Clare's diagnosis. It took me a long time to be honest with myself, but deep down I was afraid that having a "less than perfect" baby would somehow reflect negatively on our family. I



Clare at one

Photo courtesy of Jodi Moore

was afraid people would think that something was wrong with us or, even worse, with me. Over time, I discovered that my early reactions were more about my own insecurities than they were about Clare or Down syndrome. Once I could finally admit that to myself, I received more in return than I ever could have imagined possible. It is only then that I truly opened myself up to experiencing what an amazing, wonderful person Clare was becoming.

Holding On to Hope

Fortunately, when Clare was born we came into contact with a handful of medical professionals who actually knew something

about Down syndrome beyond what the textbooks said, and who, as a result, were extremely encouraging and optimistic about Clare's prognosis. Two instances stand out for me.

First, Clare's neonatologist offered some insight, "Right now you see 99 percent Down syndrome and only 1 percent baby. In just a short period of time, you will begin to see 99 percent baby and only 1 percent Down syndrome." We didn't believe him at the time, but he was right. As time progressed and Clare began to meet all of the usual milestones, albeit at her own pace, the fog started to lift, and we began to see Clare for who she was and not for her diagnosis. I no longer saw a "Down syndrome baby," but



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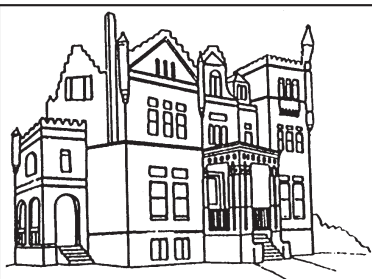
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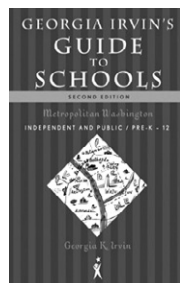
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a baby – my baby – who happened to have Down syndrome. We soon discovered that Clare, like the rest of us, was overwhelmingly unique, with her own set of traits and characteristics, likes and dislikes, strengths and weaknesses.

Second, when we asked Clare's geneticist, who is known for not pulling any punches, what the best-case scenario was that we could expect for her, he immediately responded, "The sky's the limit." He went on to explain that it wasn't too long ago that parents were advised to place their child with Down syndrome in an institution. None of the therapies that are regularly provided today even existed, and children with Down syndrome weren't provided an education. Today, he explained, with early intervention services and inclusion in the classroom with typically developing peers, experts are finding that the IQs and overall potential for individuals with Down syndrome is much higher than ever imagined possible. So only time would tell.

We decided then and there not to impose, or allow others to impose, artificial limits on what Clare would be able to learn or accomplish. We would hold her to the same high standard as our other children; we would expect her to do her very best. In return, Clare has continuously exceeded our already high expectations of her on an almost daily basis. We are hopeful that Clare will graduate from high school with a full diploma one day and that she may even go on to college, assuming that is what she chooses to do. Regardless of what path she takes, we've come to fully expect that Clare will lead a happy and fulfilling life as an adult.

Living in the Present

All of the initial doctors' visits indicated that Clare was a relatively healthy child, as are most children with Down syndrome. Shortly after her first birthday, Clare underwent a surgical procedure to repair one of the two holes in her heart, the other having closed on its own. Everything went well, and her heart is no longer a concern for us. Other than that, Clare's biggest recurring medical issues have been reflux and constipation, which, although stress-inducing at times, are treatable by medication.

Kaely and Clare have a younger brother, Kieran, who recently turned 2. They keep my husband and me more than busy and entertained. Our home is filled with the chatter, laughter, banter, stamped-ing and semi-controlled chaos one would expect to find in a house with three children under the age of 6. And I'm happy to report that Clare is right there in the mix!

Today, Clare is very much a typical 3 ½-year-old. She rides the bus in the mornings with her big sister to our local public school, where the girls attend preschool and kindergarten, respectively. Clare is one of 12 students in her class, which consists of children with and without disabilities. Three afternoons a week, she attends a private day care program (with her younger brother), where she is the only child in her class with a disability. But she hasn't let that hold her back and, fortunately, neither has anyone else. Clare fits right in with her classmates and thoroughly enjoys being one of the gang, running, playing and jumping on the playground. She began jumping a few months ago, and she hasn't stopped since! She is outgoing,

Looking back over the past few years, our lives indeed changed dramatically after Clare's addition to our family, but the changes have been overwhelmingly positive ones. My husband and I have come to look at virtually everything in our lives through different eyes.

funny and smart. Yes – smart. She is curious, inquisitive and has an incredible memory.

Clare is playful and has a great sense of humor; her smile and laughter are absolutely contagious. My husband and I always discuss how difficult it is to stay mad at Clare when she misbehaves, especially when she looks up at us, all squinty-eyed, with that toothy, ear-to-ear grin. She gives the best hugs in the world, hugs that make all my worries and stress simply fall away.

While we have some extra weekly therapies and semi-annual doctors' appointments, for the most part, our daily lives have remained very much "normal." The weekdays are busy and hectic, with both my husband and me working full-time jobs and spending our spare time transporting the kids to and from various programs and events. Our nights are filled with making dinner, playing with the kids, getting ready for bed and reading books together. I'm sure that most parents could relate equally well to our weekends, when we are faced with a barrage of birthday parties, play dates, family outings and activities.

Looking back over the past few years, our lives indeed changed dramatically after Clare's addition

to our family, but the changes have been overwhelmingly positive ones. My husband and I have come to look at virtually everything in our lives through different eyes. Now we are much more likely to notice all the little details making up our days. We have been blessed with a keener sense of what truly matters in life and what is just "fluff." Every day we feel immensely blessed and let all our children know just how special they are to us. I feel that we have become stronger, kinder and more sensitive to other people and their individual issues. We are more understanding and respectful of people's differences. And – in a word – we are happier. It's hard to explain, but it's true. Our lives have taken on additional meaning, additional focus.

And I've come to understand that Clare is no less a miracle simply because she has Down syndrome. I believe with all my heart and soul that Clare is exactly as God intended her to be. Given the choice, we wouldn't change a single thing about Clare. We think she's perfect. Just perfect.

Adrienne Vadell Sturges, her husband Kevin and their three children live in Dickerson, Md. She is an attorney in Gaithersburg. You can reach her at avsturges@aol.com.

Additional Information

There are local support groups and other community organizations directly involved in providing services to families of individuals with Down syndrome. If you would like additional information, or if you would like to contact a support group in your area, contact the National Down Syndrome Society (NDSS), www.ndss.org, 800-221-4602 or the National Down Syndrome Congress (NDSC), www.ndsc-center.org, 800-232-NDSC.

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