

For One Woman, An Unexpected Gift
A Mother Comes to Terms With Her Child's Disability

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At the beginning of the year, the American College of Obstetricians and Gynecologists came out with the recommendation that all pregnant women, regardless of age, be screened for Down syndrome early on. As a new parent of a 9-month-old daughter who happens to have Down syndrome, this news leaves a bad taste in my mouth.

This issue is bound to bring up a lot of contention in the abortion battle, and I don't care to step into that fray beyond stating that I am pro-choice. I do, however, feel the need to say something about the realities of life with a child with Down syndrome.

Although there have been moments over the past nine months when I have indulged the fruitless wish that my daughter didn't have Down syndrome, I have never for a moment wished that I didn't have this cheerful, vivacious person in my life. Sure, it is stressful and sometimes frightening to be the parent of a child with a disability. But I think you would be hard-pressed to find a parent who will tell you that it isn't stressful and sometimes frightening to be the parent of any child.

There are many ways to tell our family's story. The most optimistic version starts today and works backward. The most pessimistic starts with our meeting in the hospital with the geneticist. I think the most accurate begins with the end of my pregnancy, just before Adara entered our lives.

My husband and I were not great fans of modern American medicine, and so we had been planning a home birth. I'm 31, and I had a wonderful, easy pregnancy until the last month or so, when I developed a mild case of

preeclampsia, which is characterized by high blood pressure in the mother and can cause low birth weight and other problems in the baby. No

more visits with the midwives over a pot of tea in our living room. Now I was spending up to four hours a week in the doctor's office, getting blood drawn, attached to a fetal monitor, waiting and worrying. Now, nothing was certain and we felt like we were at the mercy of this big, inscrutable medical community.

In part to put an end to the worrying, we decided to induce labor as gently as we could. There were complications, and Adara was born by Caesarean section at a hospital just after 11 on a Monday night. Though this was far from our original plan of a home birth in a birthing pool, we were just delighted to have a baby. I will never forget the moment the nurses from the neonatal intensive care unit left the room, assuring us that our baby was healthy and strong, if a bit small.

Relief swept over me, and I focused on the little bundle of eyeballs and red hair that David brought over to my bedside to greet me. When I said hello, her eyes swiveled to my face, and we shared a stare of recognition. Here was the natural connection I had been waiting for.

The relief lasted until about eight hours after Adara's birth, when her pediatrician came into my room to meet all of us. As she poked and prodded with a clinical tenderness, she started a stream-of-consciousness monologue of what she noticed about our baby.

She was muttering away about ear placement, the spacing between the toes, and that unfortunately named simian crease. The veil of uncertainty began to drop over us once again as we wondered what could possibly be wrong with this perfect child so freshly introduced to the world.

The pediatrician insisted she wasn't convinced there was anything wrong with Adara, but there were enough markers to merit a genetic test: Just another blood draw; it could be done in the hospital, and the results would take up to two weeks to come through.

It turned out that we got the diagnosis of Down syndrome just three

days

after Adara was born: The hospital expedites the results if they are irregular.

Our time in the hospital is something of a blur, though certain clear images come through the fog. There was the wretched meeting with the geneticist, who, as David said, had the bedside manner of the two-by-four he should have been hit over the head with. There was my sister bringing homemade food and playing Scrabble with my stepbrother

on the window seat. Adara meeting her grandmothers, a grandfather and a

great-grandmother. I remember watching David sleeping with his new baby

on his chest in the early-morning hours; the three of us trying to share the hospital bed on the night we learned the diagnosis, sitting together and comforting each other in our fear and confused grief; and throwing open the curtains in an attempt to escape that little room.

And then, on Friday, they let us go home. We walked into our house, cleaned from top to bottom by my mother and sister. The refrigerator was

full of food, and there were fresh, bright flowers in every room.

David's family arrived in tides to visit and eat with us and meet Adara, and we had a wonderful weekend, seeing for the first time that there might be some hope for normalcy to return to our lives.

On Sunday, my mother and sister left. We had all agreed that we needed

time and space to be a family of three, but none of us was prepared for them to walk out the door. The tears flowed freely that night as we were left alone together with a fridge full of food, flowers beginning to wilt in their vases and the weight of all our fears falling over us again.

We were afraid of the medical side of Down syndrome, both in terms of the difficulties that Adara might encounter on her path through life and in terms of having to embrace the medical community and countless doctors' visits. We were afraid our lives were going to be overrun with therapists and experts telling us all the things we had to do to fix our child. And, mostly, we were afraid of our own ignorance of the task at

hand. We had been planning to parent by instinct. But how could our instincts ever guide us through this unnatural-seeming situation? We felt alone and lost, and very much in love with this tiny creature who needed us so much.

I remember in that first week home feeling as though I had won the lottery, but the winnings were in a foreign currency from a country that could not be found on any map. In order to convert my winnings and spend them, I would have to identify and locate the country, figure out how to get there, learn the language and make the long journey to a strange new place. As much as I love a good adventure, the task seemed huge.

The need to keep Adara fed and growing carried us through those first weeks. She was so tiny that we left the hospital with strict instructions to get food into this child as often as we could. Each feeding for the first 2 1/2 weeks involved more plastic paraphernalia than I care to remember. But more important, each feeding required David and me to sit forehead to forehead on the bed, Adara at my breast with David supplementing with a syringe as she learned to suck. This method, though time-consuming, provided our family with a level of intimacy that I wouldn't trade for anything.

We were so busy with baby care that the trauma we felt faded. And Adara seemed to be doing very well, bulking up in front of our eyes. Nevertheless, we approached our first round of doctor visits with a certain amount of trepidation, unsure that we could trust what we were seeing.

In those first few weeks we had several appointments with the pediatrician and the lactation team. I began to feel like these meetings were part of a conspiracy of confidence-building, as our providers confirmed what we were seeing. With each visit we relaxed a bit more, reassured that our instincts could inform us. Maybe this wasn't going to be all that different from parenting any other child.

Then there was the appointment with the cardiologist. Adara's nurses

had noticed a heart murmur in the hospital, so we were back for an echocardiogram. We sat in the examining room, David holding Adara as the technician attached the wires and I cowered in a chair behind them, convinced that half her heart wasn't pumping blood at all and that there was a hole the size of a quarter in there somewhere.

When the wires were detached, we went upstairs to meet the cardiologist.

The doctor didn't flinch when I let out a whoop of relief as she interpreted the results. For now, anyway, Adara was okay. There was a hole or two, but they didn't require immediate attention. We would not have to slog our way through David's brother's wedding that weekend with the secret knowledge that Adara was about to undergo heart surgery. This will probably be a reality down the road, but for now we can breathe easier. I never knew I could feel so lucky.

That is not to say that we were done grieving. But as the days passed, the waves of sadness grew farther apart and less wrenchingly painful, and we settled into a routine.

Today Adara is 9 months old and a happy, healthy child. She loves going to swimming lessons with her dad and playing with the dog. She has mastered the arts of rolling over and sitting up, and is trying to get ready to crawl. We are working with a wonderful physical therapist to integrate "therapies" into our daily routines and play. She loves squash and carrots but isn't so sure about spinach and bananas. She likes to wrestle and giggle and chew noses and chins, and can play a rollicking game of peekaboo. She loves to sit quietly and listen to a good book. She is engaging and talkative, and without question the cutest baby I know. In short, she is doing all the things a baby does, and her parents are doing their best to keep up with her newest tricks.

As I look back over the past nine months, I realize how inappropriate the lottery metaphor was. There is no need to convert this prize into any other currency in order to collect on it. I wake up every morning to a smile from Adara and spend the next hour laughing in bed with the

most

serene and cheerful child I could ever hope for. We have a long journey ahead of us, and I am sure there will be difficult times along the way. But I also know that we as a family have the strength to get through this with dignity, and I am confident that we will find plenty of opportunity for fun along the way.

I have long said I am one of the luckiest people I know. This belief has been shaken a couple of times in the past months, but I will stand by those words today. Life is a wild journey; our job is to make the most of it. *

This article is adapted from a piece that ran in the Chronicle, a newspaper in Barton, Vt. Comments:health@washpost.com.