I received my daughter's Down syndrome diagnosis through a phone call the day before she was born. I was referred to Maternal Fetal Medicine for an ultrasound and a visit with a genetics counselor and doctor two weeks before that. All the information I had before walking into that appointment was that my previous seemingly routine ultrasound had shown "Prominent fetal tongue is consistently observed extended between or beyond the lips throughout this study. This raises the question of macroglossia." Between her tongue and some scans throughout my pregnancy showing a short femur and at one point a dilated renal pelvis, I had concluded through some extensive online research that she must have Beckwith-Wiedemann syndrome (BWS). I did all the research I could on this syndrome and went to the appointment prepared to hear the geneticist confirm my suspicions. Instead, at this appointment we discovered that my daughter likely had a heart defect and we'd be referred to a pediatric cardiologist for a fetal echo. We were also told that they believed our daughter likely had Down syndrome. When asked how likely, the genetics counselor told us it was greater than 50% chance. We walked away from this appointment stunned and confused as to how they hadn't seen it before. I didn't know that people were still getting a birth diagnosis of Down syndrome. That weekend, while waiting for our daughter's fetal echo, I researched my two most pressing questions. Will I be able to baby wear and will I be able to breastfeed? Thankfully, I found many resources and advice on how to achieve both successfully. The most profound advice that I found was that with patience and persistence we could achieve both eventually.

The next week, I attended the fetal echo alone due to covid restrictions in 2020. I was left to relay the news of my daughter's defects over the phone to my husband parked outside while the doctor listened in to help me explain the specifics. He believed the most likely defect was a minor atrial septal defect or ASD, but that a more serious coarctation was a possibility that would require immediate surgery at UVA or Duke hospital. We would only know after her birth through an echo.

Our days blurred together as we frantically researched to prepare, but also prayed that our doctors were mistaken. Finally two days before she was born, and before getting the results of the blood test that confirmed her diagnosis, I went to the hospital with contractions. The doctor on call informed me that I wasn't progressing and should go home and schedule an induction of my third child because I'd likely need a lot of specialists present at her birth. The next day when I saw my midwife, she reassured me that things would be fine and that I'd likely have her without interventions.

She was right, the morning I received the call from the genetics counselor, I was having painful contractions and that night I'd be headed for the hospital. Amelie was born early the next morning. She made a quick entry into the world. She was purple and rushed to the corner of the room to receive oxygen. Meanwhile, the doctor present was very congratulatory and reassuring. I was able to hold her a little while later and she thankfully spent the majority of the time with us in our room, only being taken away for ultrasounds, echos, bloodwork, and other testing. While this was a departure from my previous relatively uneventful births that were uninterrupted bonding time. It seemed the more they took her off to the NICU to be probed and tested, the more I craved holding her.

When doctors came in, we held our breath waiting for results, and thankfully, one after another we were given the best case scenario. Minor heart defect, no renal swelling, regaining weight from being bottle fed breast milk. The only concerns we left the hospital with were two failed hearing tests, but even that couldn't dampen that despite our preparation for a possible NICU stay, we were discharged from the hospital three days later with our baby girl in our arms during our Muslim holiday of Eid al Adha. We were overjoyed to be able to return to our two older children and celebrate as a family. Eventually, she passed her hearing test, learned to breastfeed exclusively, and I to my eternal gratefulness was able to wear her in a baby wrap for several months. She has brought our family joy, love, compassion, empathy, and a source of education on the systemic challenges that people with disabilities and their families face. Through her, we are connected to an ever supportive wider community of self advocates and families. I am eager to learn from and advocate for her and others.

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Ayah Ibrahim, Ph.D.
Disability Advocate