

My name is Alina Vanessa Jimenez and live in Gaithersburg, in Montgomery County. I am a proud mother of 4 beautiful children, 2 boys in this world and 2 girls born still in January 2019. This is a brief part of my twin daughters Rafaela and Elizabeth's story in support of HB1112/SB891.

In May 2018, my husband and I learned we were expecting twins after undergoing fertility treatment to conceive. We were beyond excited and amazed that not only one, but two babies were on their way. In late July 2018, at our 12 week gestation appointment, we learned the noninvasive prenatal testing (NIPT) results were abnormal, the results showed a possibility of Trisomy 18 (also known as Edward's Syndrome), a rare disease considered non compatible with life. Because our twins were both in separate sacs and had their own placentas, they were initially considered fraternal twins (not identical). My doctor stated that with this rare disease, only one twin is likely affected and to consider a "selective reduction." We were referred to a perinatologist (a maternal-fetal medicine doctor) that had the skill to perform such "reductions." In addition to our religious faith, the parent instinct of protection and care was turned on to full power, and we informed our doctor that we were keeping both of our babies, and needed help to care for them during their development. We were referred to the same perinatologist for these services.

At our perinatologist appointment, we were also recommended to perform a selective reduction. But we also learned that if we kept both babies to term, the baby with the Trisomy 18 would not affect the healthy baby as they were independent of each other. This gave us more cause to care for both of our babies and rejected the idea of performing a selective reduction. However, the doctors and geneticist continued to remind us of termination at each follow-up appointment, despite us asking them to stop asking us the question. The reason they kept bringing it up, was because our window to terminate the pregnancy was closing. We were referred to the Trisomy 18 Foundation, which was helpful to provide disease information and an online Facebook group for families affected by the disease. While helpful, the foundation was limited with resources I looked for. I reached out to the fertility clinic for help, only to be referred to the Trisomy 18 Foundation again. So I turned to my church pastor in hopes of prayer and support. He was so gracious to receive my husband and I with open arms, and also referred us to the organization of Isaiah's Promise (IP). IP is an organization that supports parents carrying a pregnancy to term after a severe or fatal prenatal diagnosis. As soon as I learned about IP, I realized I found the help I had been looking for, a help I did not know how to describe at the time since my mind was full of anguish.

IP was wonderful in supporting my pregnancy. They helped us find joy in my pregnancy and to cherish the few weeks we had with them. While doctors initially thought only one twin had the disease, it turned out that both of twins had the disease. Rafaela (Twin B) passed first, and weeks later Elizabeth (Twin A) passed. Both times, IP was there to support us through the pregnancy and loss of each twin. IP also supported us through our grief after our loss and continues to be a wonderful resource to date. Through my pregnancy I also learned of similar organizations and was so happy to learn that there are wonderful people around the world providing this service. However, it saddened me that it was difficult to find such resources when you don't know what to look for after receiving a life limiting diagnosis – there is so much anguish and distress. Such resources should be made available from the beginning by doctors providing the referrals and diagnosis, including fertility clinics since they see hundreds of patients a year. I share my twins' story because they were living beings as we are, and they

needed the support as much as my husband and I needed the support. No parent should only be given the option to terminate, they should be provided all options and all resources to help them make an educated and conscience decision. No parent should have to go through a fatal prenatal diagnosis alone and this why I support HB1112/SB891.

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