

Testimony in Support of HB 2307 - Prenatal/Postnatal Diagnosis Information Act (HB 2307)

Kansas House Health & Human Services Committee

Scotti Brackett, Parent Advocate, Olathe, Kansas

February 10, 2025

Dear Committee:

I appreciate the opportunity to share my family's story about the importance of passing the **Prenatal/Postnatal Diagnosis Information Act (HB 2307)** which aims to provide *and expand resources and accurate information when a woman and her family receive a prenatal or postnatal diagnosis for disabilities, like my son.*

My son was born with down syndrome in 2016. At our 20 week ultrasound, they noticed something on his heart. Everything else looked good. We briefly spoke to a genetic counselor about prenatal testing options, and chose the amniocentesis. The genetic counselor calculated our risk for trisomy 18 and 21. We then developed a plan to deliver the results. At my job, I cannot readily answer the phone, but my husband can. The plan was for the genetic counselor to call my husband with results, and we also signed a form allowing the counselor to leave results on a voicemail.

About a week later, I was at work and missed a phone call. It was the genetic counselor who left a message asking me to call her back. I immediately called her back and she did not answer. I called repeatedly for the next 30 minutes and left multiple voicemails, and she never called back. And she did not call my husband at all. I was suspicious as to why she did not follow our written plan. It wasn't until 5:06 PM the next day when she returned my phone call. She Asked me what I was doing, and I replied that I was driving on the highway to pick up my other children from daycare. She very abruptly said, "it's not the results we were hoping for, there is a third copy on chromosome 21." I began crying and she acknowledged that I was upset and said she would Call me back the next day. The entire phone call was 27 seconds long, and I was driving on a highway. This was a very dangerous situation for me to be in, and the genetic counselor seemed to have no consideration for my physical or emotional well-being. The genetic counselor never called me back.

I am confident that charging the Kansas Council on Developmental Disabilities (KCDD), a statewide organization dedicated to supporting all Kansans with I/DD, their families and caregivers with the responsibility of expanding accurate, up-to-date information is the right approach. This bill will help future families, alongside the next generation of individuals with I/DD, receive proper support, information, and care when facing a diagnosis. KCDD would lead efforts to partner with state disability organizations to promote accurate, up-to-date information about Down syndrome and other conditions.

Thanks for allowing me to share our story.

Sincerely,

Scotti Brackett, RN, APRN, FNP

Olathe, Kansas

sbrackett@kumc.edu