My name is Kathy White. My husband is a retired Marine and we made Kansas our permanent home 16 years ago after he was stationed at Richards Gebauer in Missouri. We have been residents in Cedar Creek, Olathe for about 3 years. I wear a couple of different hats: 1) I have been on Staff with FASD United for nearly 2 years. 2) I also support Foster Care Ministry for the Archdiocese of Kansas City in Kansas, overseeing 107 Catholic Churches and schools in Kansas.

Over 7 years ago, my husband and I had 5 children–ages 5 to 15 years old. We had a full and busy life when we learned about an adorable 3-year-old orphan in Johnson County. As a faithful family, we felt called to help–we invited him to stay with us until his grandparents could figure out a plan for him (his single birth mother had recently died) and they asked us to adopt him 2 weeks later.

As a professional Mom, I knew he was significantly delayed. And because we have a great village, our pediatrician, OT/PT, Speech therapists all agreed–something deeper is going on with him. He has continued with significant medical needs: my adopted son has more providers and is seen in more clinics and has had more surgeries at Children's Mercy than all other 5 children COMBINED.

Zachary was diagnosed with partial Fetal Alcohol Syndrome–which is one of the many diagnoses under the Fetal Alcohol Spectrum Disorder Umbrella, if you will. It is a brain-based disability that affects his whole body, and he will never outgrow his brain-based difference.

The challenging thing about Zachary is this: his brain-based difference is all internal. So, while he is adorable and cute, his disability is not outwardly visible. He is also charming. But his development is scattered–that is, he has times when his brain is operating as it should, and he behaves as other children his age. But more often, he has scattered maturity, which means his behaviors are more consistent with a child who is ½ to ⅔ his chronological age. So, while he is chronologically 10 years old, he behaves more like a 5-year-old. In our home, we call it dysmaturity. If he doesn't like something, he may end up on the floor, crying. Which is common and expected in littler kids, but in a 10-year-old–it looks very different. He also has multiple co-existing conditions, because FASD is a whole-body diagnosis, it affects everyone differently. This affects how Zachary navigates the world, how he accesses his education, and as with all families with individuals with an FASD, I have countless meetings every year with educators on how to support him best in the classroom setting. And they don’t understand.

I continue to learn and have done a deep dive on how to best support Zachary, receiving extensive training, and I would dare say I am one of the leading experts on FASD in our state. My work with FASD United makes my perspective unique: I am front and center with best practices, and I support individuals, young and old, as well as professionals, educators, doctors, researchers and caregivers across the nation. I was instrumental in gaining the support of many of our Federal Legislators who supported the FASD Respect Act (which was included in Support Reauthorization Act HR2483) which passed in December. I am meeting with Representative Davids next week, and return to DC next week to touch base with Senator Moran about funding and state appropriations. In fact, a local Kansas Senator introduced SB249 (now referred to the Committee on Public Health and Welfare) to establish a FASD Task Force for a coordinated effort.

I’m sure you’ve heard by now, research shows 1 in 20 children have an FASD–mostly undiagnosed or under diagnosed–that’s basically 1 student in every classroom. I believe House Bill 2203 will help qualify students for special education services, so students like my son can get the support they need and not get reprimanded for behaviors–behaviors that are a result of their brain-based disability. It will help educators to offer support, accommodations and interventions in the classroom for kids like my son, protecting against the adverse outcomes students will experience if they aren’t supported. Thank you for your time.