

Kelly Kuhns

House Bill 214

Senate Health, Human Services, and Medicaid Committee

December 11, 2017

Chairman Burke, Vice Chairman Beagle, Ranking Member Tavares, and members of the committee, thank you for allowing me to testify today in favor of House Bill 214. My name is Kelly Kuhns and I am the mother of a ten-year-old boy, an eight-year-old girl, and a two-year-old boy with Down syndrome. Please note that I stated a boy first and then the Down syndrome. Oliver is a person with Down syndrome and isn't defined by Down syndrome. Not only am I a mother of a child with Down syndrome, but I am also a labor and delivery nurse. I am here today to share my story in support of this legislation.

When I was approximately 14 weeks pregnant, my obstetrician offered cell-free DNA testing. For those of you who do not know about cell-free DNA, it is a sample of blood that is taken from the mother and the ability to separate baby's blood from mom's blood to look at fetal chromosomes. This testing is not only able to determine the sex of the baby, but it will also identify chromosome abnormalities. On December 2, 2014, my doctor called me and stated, "Your blood work results came back positive for Trisomy 21. I am sorry your son has Down syndrome". She then went on to state that I could come in to the office to discuss my options. An hour later I met with my doctor and we discussed abortion and continuing the pregnancy and my potential future including a child with Down syndrome. She encouraged me to think about it and that she would support whatever I decided to do with the pregnancy. She didn't push me or encourage me to abort or continue the pregnancy. My options were laid out to me in a very

practical and to the point manner. Then she referred us to Maternal Fetal Medicine for additional testing.

I left the office feeling as though I was given a death sentence. I didn't know of anyone with Down syndrome. I never see people in my community with Down syndrome. At that time, I was a nurse in the ER and I never had taken care of a person with Down syndrome. I felt so alone and alienated! I laid in my bed and cried for hours. I grieved deeply for my lost future with this child. Once I was able stop crying, I did what all parents do and I got on Google and searched "Down syndrome". This made me feel even worse. As a nurse, I focused on medical complications and conditions that he would be at increased risk of because of the Trisomy 21. This only made me feel even more lost and heartbroken.

A week later, I met with Maternal Fetal Medicine. They performed an ultrasound and the doctor offered an amniocentesis. The amniocentesis is the only test to confirm the baby would be born with Down syndrome. We declined the testing because they would have to have gone through my placenta to get the sample needed for testing and that would increase my risk for a miscarriage. That was a risk I wasn't willing to take. I had wanted a baby so desperately! Who am I to decide whether my baby should be allowed to live or if I should end his life? I saw him moving and wiggling during the ultrasounds. I saw his heart beating! I had a connection with this unborn child and I fell in love with him before I even saw him. We wanted this child and a Down syndrome diagnosis wasn't going to change our love for him.

I met with a genetic counselor and was given printouts on Down syndrome and a list of resources. I couldn't stop looking at the pictures of the babies and toddlers in the printouts. They were adorable! Yes, we were told what our future would look like with this child. We were told children with Down syndrome are an increased risk for respiratory infections,

gastrointestinal conditions, heart conditions, feeding and digestion issues, hearing loss, vision impairment, and low muscle tone. We were told of all the different therapies he would need and all the additional work that would be involved with raising a child with special needs. But we were never told how amazing our lives would be with Oliver in it. Nobody told me my face would hurt from smiling at him or that we would celebrate reaching milestones differently than we did with our typical children. Nobody told me that my older two children would learn life lessons that other children would never get the opportunity to experience. My other children have a deep compassion and heart to serve others that are deserving! The focus isn't on the disabilities. It is on the abilities. My sweet Oliver laughs, plays, walks, eats, signs, and loves fiercely! He isn't any less of a person because of his extra chromosome. Honestly, it makes him more of a person.

Thank you, Chairman Burke, Vice Chair Beagle, Ranking Member Tavares, and members of the committee for the opportunity to share my testimony and testify my support for House Bill 214. My son Oliver and the other people that have been diagnosed with Down syndrome deserve to live and should not be subjected to the discriminatory practice of selective abortion. I encourage you to vote in favor of House Bill 214.