

March 13, 2018

Chairman Burke, Vice-Chair Beagle, Ranking Member Tavares, and Members of the Health, Human Services and Medicaid Committee, thank you for allowing me to provide proponent testimony on House Bill 332, which would ensure that individuals with disabilities will not be banned from an organ transplant waitlist solely based on their disability.

I write this written testimony as a representative of the Autism Society Greater Cincinnati, but my professional advocacy role often coincides with my personal story and I want to take this opportunity to share from both perspectives. This bill is doubly meaningful for my family because I have two children with disabilities. My son, Jack, is seven years old and is autistic. My daughter, Evie, is five years old and has Down syndrome. When you are a parent who receives these diagnoses for your only children you have many different challenges to face and decisions to make. One decision is clear: you will do anything to keep your children healthy and happy. Individuals with autism and people Down syndrome are living longer and more independent lives today than ever before. Jack and Evie have just as much of a right to live long and happy lives as any other child. They both have a bright future and their respective disabilities should not, in themselves, hold them back. My children are both attending public school in their general education classes. They ride horses every Saturday. Evie loves gymnastics and Jack loves riding on his scooter and digging in his sandbox. My children bring our family immense joy and we are proud of exactly who they are.

Jack was diagnosed with autism when he was 18 months old. I worried that his diagnosis might be a detriment to his education or having a job someday. I never considered that his diagnosis would keep him from getting an organ transplant if he needed one. Many families in our Greater Cincinnati community have these same worries when they start to see signs of autism. Our role at the Autism Society, Greater Cincinnati is to improve the lives of all affected by autism by being a trusted, caring, and leading resource in the community. We at the Autism Society want families to seek support and resources without worrying about possible discrimination when it comes to healthcare decisions.

Jack is very healthy but my Evie has had several medical procedures. She had open heart surgery at a year and has had several surgeries to open her airway due to her secondary diagnosis of sleep apnea. People with Down syndrome often have medical complications, but when your child needs surgery you don't hesitate to ponder the twenty-first chromosome. When the pressure in Evie's heart wasn't normal, her heart surgeon explained that she needed surgery, explained the risks and scheduled the date. At no point was her diagnosis of Down syndrome discussed as a reason not to do the surgery. And it shouldn't be.

If Jack or Evie, or any child with a diagnosis of autism or Down syndrome or any disability, needs an organ transplant they should be put on the waitlist like everyone else. Having your child evaluated and then diagnosed with a disability should not be counted against him or her for a life-saving measure. The autism community does not need another barrier to get a diagnosis that is necessary for early-intervention services. Individuals with Down syndrome are valuable members of our community who happen to have the medical complications that put them at risk for organ failure. So, it is my hope that HB 332 will prevent discrimination against Jack and Evie and all people with disabilities if they need an organ transplant. I also ask that the following amendment be added to the bill to ensure life-saving treatment be given priority of the civil docket: "The circuit court shall give priority on its docket an expedited review to a claim brought under this section." Thank you for your time and consideration of this Bill.

Respectfully,

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