



October 9, 2017

Chair Huffman, Vice-Chair Gavarone, Ranking Member Antonio, and Members of the Health Committee:

Thank you for allowing me to provide 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.

My name is Kari Jones and I am the President & CEO of the Down Syndrome Association of Central Ohio. I represent over 1,200 individuals with Down syndrome—and their families—in 23 Central and Southern Ohio counties. People with Down syndrome, when given the opportunity, can become talented, successful, and independent leaders in our community. They can go to college, get married, work full time jobs, and maintain meaningful relationships.

Many of the families I represent, at one time or another has sought medical treatment for their loved one with Down syndrome due to commonly co-occurring health conditions like diabetes, sleep apnea, and vision problems. Nearly one in two people born with Down syndrome is also born with a congenital heart defect. Many of those individuals require life-saving surgeries very early on in their lives—and some may require a heart transplant or organ donation in order to survive.

Through my organization's medical outreach initiatives, we have made great strides in educating and partnering with the Central Ohio medical community in order to enhance and strengthen services to families impacted by Down syndrome. On a weekly basis we meet with doctors, nurses, specialty physicians, and future medical graduates who are eager to provide quality care to their patients. However, leaving the existing gap for medical boards to deny someone of an organ transplant solely based on their disability is not acceptable. It is important that we work towards a resolution now—before any parent is put into a situation in which they may be faced with a legal battle that could cost them their child's life. We need to close the gap.

As you have heard, I wholeheartedly support the Organ Transplant Waitlist Anti-Discrimination Bill. This bill clearly defines a human right. Whether or not a person has Down syndrome, or any other disability, should not define their access to life-saving procedures like organ transplantation. Please vote in favor of this bill so we can do the right thing for all of Ohio's families.

I truly appreciate your leadership and thank you for your support of House Bill 332.

With High Regards,

Kari Jones
President & CEO
Down Syndrome Association of Central Ohio