

March 12, 2019

Senate Public Health and Welfare

Testimony in Support of Senate Bill 194

Candice Seaman

Good morning Chairman Suellentrop and Members of the Senate Public Health and Welfare Committee. My name is Candice Seaman and I am here today in support of SB 194, which would recognize the rights of organ donors in Kansas. I currently live in Waverly, Kansas and have an elementary education degree and Master's degree in school counseling. I'm currently taking time off from working but manage to help my husband with our farm and ranch when needed on top of my other full-time job, which is being a mom of two beautiful and wild tiny humans. While I would love to still be in the school working, my condition has made it increasingly harder for me to keep a job and while maintaining life at home. I was born with Biliary Atresia, a rare congenital pediatric liver disease in which the common bile duct between the liver and small intestine is blocked or absent, so bile is unable to drain and backs up into the liver. The only cure for my condition is a liver transplant. The only treatment is the Kasai procedure and it must be done as soon as possible as an infant. Even if this surgery goes well, a child will need a liver transplant in the future.

I continue to play the waiting game that is my life. Part of me wants to go and hurry forward with the transplant, while the other part finds comfort in this familiar stability I'm in now. Due to donor shortages, it seems like you have to be near death to get a transplant. Many people are unaware of the organ in this country. While I have lots of opinions on organ donation, my main focus is on keeping organs local. I've spent lots of time informing family and friends on organ donation, even so much as to creating a private Facebook post for people in my circle. I've been amazed at the response I've received over the past year from my family and friends. There is so much misinformation and lack of understanding that goes on with organ donation.

My understanding of the organ donation program is that while they are trying to deal with a very touchy issue, there is still a severe lack of sensitivity in some areas. I have literally been waiting my whole life for a transplant. I finally, at the age of 36, make it to the list only to find out that I will have to wait even longer for the opportunity to get the organ that I need to live because local organs are going to be shipped further away — making my wait time on the list even longer, my condition worsen, and jeopardizing the outcome of a transplant when it does happen. There is no machine currently that keeps your liver going when it decides to shut down. If I get to the point that I am too sick for a transplant, the only alternative is death. Getting a liver as early as possible is my best bet.

I am blessed to live in what many refer to as the Heartland. When we someone in need, we help. If someone is hurt, we give aid. And, when someone falls, we give a hand. This is the place

I grew up in and this is the way of life I know. I would love to say that it is like that all across the United States. I have traveled some, even abroad once, but it is not always the case. Not every state is lucky enough to have these types of communities. I've even been blessed to live in a strong community that has shown me support and empathy over the years as I struggle with my ongoing condition.

Since I was born with this liver disease, I have always known that I would need a transplant but it really hasn't registered as much until this last year when I was placed on the waitlist for a liver.

When I was younger I was able to live a fairly normal life. I had hardly any restrictions but knew at some point I would be looking at a transplant. I feel this is the case of many Americans. Until something affects them or someone they know, there's a severe lack of understanding or interest. But I find that less likely the case here, as Kansans we're always looking out for our neighbors. Organ donation is a gift, something we choose to do, and something my family, my friends, my coworkers, my community members, and even mere acquaintances have chosen to do in response to a condition I have. People I barely know and people I've loved all my life give this gift expecting that someday they may be helping someone similar to me. Expecting that they are helping their neighbor, coworker, family, or someone close to them to receive this gift.

The thought of organs being shipped off and viewed as a commodity or resource like corn, oil, or beef is enough to make most cringe. Organ donation is a gift; national resource doesn't even come close to describe the choice we make by becoming a donor.

Thank you for your time this morning and your consideration of SB 194. I'm happy to stand for questions at the appropriate time.