

Thank you so much for giving us an opportunity to talk with you today about why we know that Oregon needs a law protecting its disabled citizens from transplant discrimination. My name is Sunshine Bodey and my son is Lief O'Neill. Our story is important not just because it is one of transplant discrimination, indeed Lief came perilously close, within minutes, of dying in the darkest shadow of prejudice, but he didn't. The light of acceptance and justice prevailed and he became, to mine and Stanford's knowledge, the first nonverbal person with autism to be granted both a left ventricular assistive device, an important bridge to transplant, and the transplant itself. We are here ~~not just to say that this law is necessary and important~~ <sup>to tell our story</sup> but also to help you understand the ways that transplant discrimination is enacted so that you can consider these things as you craft the language of this bill. In order for this law to be truly effective you need to understand that denying formal evaluation is one way this occurs. If no formal evaluation is made then no official denial occurs. Secondly, children with developmental disabilities need equal access to Bridge therapies, life extending devices that allow people to survive to transplant. Our story also illustrates the need for accommodation during the transplant process and, maybe most importantly, an efficient and time-sensitive mechanism for giving parents an opportunity to seek enforcement of the law.

So, our story began four and a half years ago When Lief, age 9, developed virally induced cardiomyopathy, which is a fancy way of saying that his body reacted to an ordinary flu virus by attacking his heart, filling it with fluid and enlarging it to the point that the muscle fibers broke and when the fluid was removed it would no longer be able to function. Lief had in a matter of weeks gone from an ordinary healthy kid, albeit one very effected by developmental disability, to a child admitted to Doernbecker's children's hospital at OHSU in critical condition with only one hope for survival, heart transplant.

I think it is important to understand that at the time of Lief's illness we were experiencing a most wonderful and incredible time with Lief, a time we called "Great Unveiling". Lief is non-speaking and he struggles with sensory disturbance, profound motor planning difficulties, and the perseverative behaviors that are the hallmark of those very effected by autism. Lief and I had worked very hard for six years to learn to type to communicate and it was during his ninth year that he became proficient enough at this to begin to reveal to us how he experiences his body and this life. It was an incredible time where we could finally know his hopes,

dreams, memories, feelings, and ask all those questions we had about who our son truly was. This ability to type ending up playing a pivotal role in why Stanford opened their doors to him but I would like to say that if this had happened two years earlier when he was only typing for the basic things he wanted or even not at all then he would have undoubtedly been allowed to die. Another reason this law is important. People can't until they can. Leif was a kid who struggled to sit in a restaurant for ten minutes let alone endure the grueling marathon of medical procedures that is transplant. Lief showed me and all the staff at Stanford that we cannot not know what one is capable of until they are fighting for their life. He developed new skills and abilities during this time that could not have been predicted. We could have never predicted that he would be 100% compliant with an astounding endurance and patience that exceeded most neurotypical adults let alone a young child with autism.

When we arrived at Doernbecker's the senior doctor told me "That he would promise me two things that we would know everything they knew and they would treat Lief like their own". These words were both my first real inking of the severity of my son's illness and exactly the assurance I needed to not panic and to trust them. I am still struck today with the beauty of that promise but it is not what happened. During our nine days there we were served by many compassionate and gentle nurses and doctors and for that we are grateful. But on the fifth day we were taken into a room where we were told by a team of people that two transplant hospitals on the west coast, including one in a state with a law prohibiting transplant discrimination, were unwilling to even consider Lief for transplant. The reason was explicitly and clearly stated it was his status as a person very effected by developmental disability. We were told it was unlikely any program would feel differently. I assure you there was no sense of moral outrage expressed by the staff and there was no promise of further action on their part to advocate for him. The message was clear that there was nothing to be done but wait for his death. In the words of one doctor "there is no magic heart waiting for you", but sometimes doctors are wrong and he did have a magic heart waiting for him.

At this point, I had to make a difficult decision, go spend every last second with my son before he died or spend my energy trying to launch a legal and media campaign. We started down this path but Lief's condition was deteriorating rapidly and it seemed our fight was over before it began. So, we went to be near our son. We were told the end was close, we had hours to a day. We were moved to a bigger room to accommodate the family and

friends who had come to say goodbye. We were on a free fall to what every parent will understand is just the unthinkable. What I found out later, was that one persistent doctor, not a senior member of the staff, was doggedly relentless in getting Stanford to consider our case. He sent a video of Lief typing and called Dr. Hollander, the head of pediatric cardiology, 14 times that day. So, at the eleventh hour and I mean eleven fifty-nine and 59 seconds Stanford opened their hearts and doors to Lief and he was life-flighted to Lucille Packard children's hospital.

We were cautioned it was unlikely he would survive the flight. I watched as he coded, medical term to indicate clinical death, again and again as we flew into the night. But he did survive and was put on the most total life support known to us. In the morning a doctor told me that the only ability that mattered to them was the ability to give and receive joy. The next day he was fitted with an LVAD (left ventricular assistive device) a device that does the work of the left ventricle. This is a standard bridge therapy currently used by 7,000 children and adults. Not at any point during our stay at the hospital Oregon did anyone mention the existence of this therapy or it's power to extend my sons life by years while we waited for transplant. These devices are implanted at OHSU. It was presumed that Lief was too disabled to receive this device because of the cumbersome computer and heavy batteries that hang from outside the body so we were denied even knowledge of it's existence. Lief did end up being the first person with marked developmental disability to receive an LVAD. And he rocked it btw.

The LVAD was just the beginning of what can only be described as a medical odyssey that spanned a year of continuous hospitalization, five open heart surgeries, and countless grueling procedures and ultimately culminated in the incredible experience of receiving the gift of a human heart. Lief helped change the discourse in transplant medicine from debate around "Should we transplant kids with autism" to "How do we transplant kids with autism". I was heartened to see language in this bill regarding accommodations because we struggled to get those, in part because he was the first of his kind and it was all new territory. Lief is doing well today at fourteen and still remains a model patient despite how very effected by autism he is. He might be the first person like him to be granted a heart transplant but I can assure he is not the first person like him to have needed one.

Thank you for making this law. Autism is not a disease, it is a way of being. We are the same but different. Kids with autism deserve to

I want you to see me as smart

live. Death is just a new beginning but I wanted to live. I am very grateful I received a heart.