

March 8, 2021
Senate Bill 134
Senate Committee on Growth & Infrastructure

Good Afternoon Chairwoman Harris and the rest of Committee on Growth and Infrastructure.

My name is Ashley Biehl. I just turned 30 years old, and I am a CAP attorney at the Legal Aid Center of Southern Nevada.

I am here today to speak on behalf of Senate Bill 134, revising provisions regarding anatomical gifts.

I turned 30 on March 3rd. It was a birthday I would not have seen, without my donor, Jessica, and the gift of organ donation.

In 2017, I had a heart attack. The doctors still cannot explain why; I'd been an athlete my entire life and was actively training for a 10k when it occurred. My family does not have a history of cardiac conditions, nor do I. Things went poorly and the left half of my heart died. I was placed on the most serious form of life support that exists, ECMO. After surviving an induced coma, and sepsis, I was eventually placed on the transplant list for a new heart, because my heart could not recover.

From the day I was listed, May 29, 2017, until the middle of July 2017, I resided full time in the Cardiovascular Intensive Care Unit (CVICU) at the University of Utah. Every day was a waiting game, to see whether a heart would become available that matched my blood type and antibodies. The waiting was excruciating. I had multiple central lines, including a PIIC line, and a SWAN line, which is a direct line from the veins in your neck, to the top of your heart. I could not move from my bed to the chair next to the bed without a nurse present. Same goes for the toilet, two feet from the chair. I was attached to many machines, beeping constantly, as medications kept me alive, and machines alerted the nurses if any part of my body was not operating as it should. Sleep was hard to come by and every day that passed felt like a new defeat, because, yet again, no hearts had become available. Every day consisted of the same routine—I was only permitted to move if a nurse was present. I was allowed to go on one walk around the unit per day, two, if I got lucky and the nurses had time. I was not able to shower and only two visitors were allowed to see me at a time.

As the length of my stay increased, the odds of a successful transplant decreased. My pulmonary pressures kept rising, making it so that was I was no longer eligible for transplant on certain days, because my lungs would not have been able to withstand the surgery. My heart continued to fail and the doctors worked furiously, changing my medication regime to try to keep my heart pumping for my body without the assistance of a machine. The team of professionals treating me began to disagree. Some felt I was strong enough for transplant, but some felt that I was no longer strong enough to handle it, and that I should be given an LVAD. The Left Ventricular Assist Device (LVAD) is a machine that pumps the blood for your body. The surgeons core your heart like an apple, put the pump in your heart, and then it is connected from a line directly from

your heart, out your stomach, to a battery pack that you must wear 24/7/365 until you become eligible for a heart transplant. It requires an open heart surgery, and you have an open central line for an unspecified amount of time. This means: no running, no swimming, no showering, and nightly dressing changes. To me, this option took away everything I love about life and I argued aggressively to be left on the transplant list, but as time wore on, things became more and more bleak.

Finally, on June 28, 2017, I received the call: a match had been found and my transplant would occur the next morning. On June 29, 2017, I went into surgery for over 4 hours and my heart was replaced with my donor's heart. I spent the next few years recovering. Even now, it is not an easy journey. I take immune-suppressants every 12 hours to keep my body from rejecting my heart, but I am here-I survived.

In November 2017, I was able to meet my donor's family in person. My donor, Jessica, was 26—the same age as me. We both enjoyed hiking and sushi. Jessica had registered to be an organ donor through the DMV. After splitting from her first husband, Jessica met a new man, and they became engaged, while her divorce remained pending. When Jessica was declared brain dead, the organ procurement team contacted Jessica's family and asked if they knew her wishes. Jessica's fiancé immediately stated that they had never talked about it and he was absolutely unwilling to sign the forms required for her to become an organ donor. However, Jessica was still legally married. Her husband stepped in and decided: if she had registered to be a donor, that was what she wanted, and he would honor her wishes. Another recipient received her kidney, and Jessica's life went on to mean the actual world to me and another recipient, even though we'd never met her.

Unfortunately, organ donation is something that most people don't think about until it becomes necessary for someone close to them. The United Network for Organ Sharing (UNOS) is a non-profit organization that collects data pertaining to patients waiting for life-saving transplants, actual organ transplants, and recovery rates. At present, 107,938 people are waiting for a life saving organ transplant. Another name is added to the waiting list approximately every ten minutes and twenty people die every day waiting on a life-saving transplant. One deceased donor can save up to eight lives through donation.

According to the Health Resources and Services Administration, upwards of 90% of adults support organ donation, yet in Nevada, only 41% of adults are actually registered organ donors. This rate is abysmal. Add this to the fact that Nevada has no transplant centers (with the exception that UMC does kidney transplants) and Nevadans are suffering. To even seek a life-saving transplant, Nevadans must uproot their entire lives and move temporarily to California or Utah or Arizona, where their transplant can be completed, and then must continually travel back and forth for ongoing care.

Senate Bill 134 seeks to help alleviate some of these problems by switching to an opt-out organ donation system, in which adults would choose to opt out of organ donation at DMV, rather than opting in. Many advanced countries and provinces already follow this model, including: Austria, Belgium, the Czech Republic, Finland, France, Greece, Hungary, Israel, Italy, Luxembourg, Norway, Poland, Slovenia, Spain, Sweden and Turkey. Consequentially, Spain has the highest

donation rate in the entire world. The United Kingdom switched to the opt-out donation system in May 2020, and recently, Nova Scotia became the first Canadian province to adopt an opt-out organ donation system. Nevada would be at the front end of what I believe will be an up and coming trend in organ donation across the United States over the next several years.

To address a few potential concerns: all major religions support organ donation, and for those who choose not to donate for religious purposes, they would, of course, be eligible to opt out, just as anyone else would. Further, this bill would eliminate the myth that doctors do not help save people who are organ donors. While this is, of course, a myth to begin with, a common concern is that medical professionals will not work as hard to save people who are registered organ donors. Senate Bill 134 would eliminate these concerns because everyone would presumptively be an organ donor, unless they opted out, which no member of the care team would know in advance. Additionally, being an organ donor provides some families with a sense of closure and security. My donor's mom has reached out several times to let me know how much it means to her knowing that a piece of her daughter lives on inside me, and that, despite the tragic loss of her daughter, her life went on to mean something so powerful—it literally saved two other people.

In conclusion, approximately 7,300 people die every single year in the United States waiting for an organ transplant. Senate Bill 134 seeks to help alleviate that burden and reduce the number of unnecessary deaths by making more organs eligible for donation. Further, 90% of the population supports organ donation, and by approving an opt-out system, people would still have every freedom to choose not to be a donor. This bill has the potential to really truly save many many lives. The uncertainty of waiting on a transplant is excruciating; I know firsthand. I full-heartedly support Senate Bill 134 and respectfully urge the committee to move forward with the passing of the bill. I am more than happy to answer any questions you may have.

Thank you.

Ashley N. Biehl