

March 16, 2021

RE: HF 1080 Written Testimony

Chair Stephenson, Vice Chair Kotyza-Witthuhn, and members of the House Commerce Finance and Policy Committee:

Thank you for taking the time to listen to our story, but most of all Bryce's story. I say story but this is our life.

Please allow us to share Bryce's medical struggles of unfair treatment and his journey to receive a life-saving organ transplant. This happens all the time here in Minnesota along with many other states. Bryce is an 18-year-old boy that has a twin brother (Eric) and a younger sister (Tylee). All three are incredibly kind-hearted children. The boys have a special gift, however. Both have severe Autism. Bryce is mostly non-verbal while Eric is limited in this regard. These boys have the purest heart and have helped people, unbeknownst to them, grow on their paths to become better people. The boys have a gift that makes you slow down and realize what is going on around you and have you look for the positive in the middle of so much perceived chaos. They are a true example of who we all should strive to be. No judgment. Only the purest kind of unconditional love.

In the spring of 2018, our lives changed. The unthinkable materialized and Bryce was now in the fight for his life.

I brought Bryce to the Children's Hospital. We walked into the ER and within two hours of being there I was told his liver was not functioning normally. Bryce was put into the hospital for about two weeks. Keep in mind the four of us had never been apart before, and Bryce had never been away from home. However, Bryce did great. By the time our stay was done, it was determined that Bryce was for sure in liver failure. They got us set up with their Liver Transplant Doctor, and for Bryce to be taken off of his medication for his autism to see if this was adding to it because, at that time, they didn't have a reason and the medication was an easy possibility. So back home we went and took him off all of his meds. This made it hard for Bryce to be able to handle the environmental input, however we kept at it. There was no change in his labs and no improvements to his liver—matter of fact they got worse. At this time, they started testing his twin brother to see if they could help narrow down a reason, only to show that Eric also had liver issues and at that time they felt that he was maybe five years behind Bryce with the liver failure. We kept going to see his liver doctor every time with new demands being made, yet by our next appointment the demand was met by Bryce, if it was from losing weight, to behavioral demand, to being able to do testing with no sedation. Bryce met all of these demands and had the proof of it being done in their hospital, or by behavioral professionals. By this time Bryce was giving lab draws with no issues, keeping bandages on, and was now falling asleep himself during the scans. This had all been accomplished in a few months of time. Our family felt like we were on the right road to being able to get him listed for his MELD score was already high enough to be listed for transplant before we left the hospital and was increasing as time went on. By about three months from our stay with Children's and many appointments in between to make sure that Bryce's body would be able to handle a transplant. I would like to mention that he PASSED on EVERY ONE of them. Bryce got even sicker what felt like overnight I knew as a mom knows that this was moving fast and I needed answers—he needed them. For his next appointment I had my parents come along to help with the kids and so they could also hear what was going on. This appointment was just like all the past appointments with labs and measuring his stomach and then scheduling the next appointment. I then asked if he has been listed and is there a chance of a living donor as my mom and I have the same blood type.

In this two-minute time frame our life was put to a complete stop. As Bryce and I sat in the room along with his brother, and sister, and grandparents the words came from his liver doctor, "I have not listed Bryce, I don't believe that he will be able to handle the transplant because of his autism. Even if I was to present him, ethics would appeal it, that he won't be able to contribute to the world as another typical person in need of liver". The fear and the pain that I had for not only for Bryce but all my children to hear that someone did not feel his life was worth

saving because he has autism. I will never be able to put it into words, as tears ran down my face and I could barely breathe, I managed to have my parents remove the kids and then asked the doctor how long he had to live because he is not doing well. One to two years and maybe less on how fast he is moving along.

Thankfully, we don't give up easily, and we have determination to never let someone tell us that there is no hope. Within two weeks I managed to get Bryce into the Mayo in Rochester with a wonderful liver doctor that not only treated Bryce medically, but treated him with respect.

By the time we left this three-hour appointment, Bryce had appointments for his treatments to help get his vitamins up and a plan on how to help maintain them and was sitting up for yet another liver transplant approvals in order to make sure that his body would be able to withstand a transplant. As the first one, Bryce passed through with flying colors, no behaviors for any of these tests or appointments. The big day was finally here. Bryce was being presented to the team to be listed for transplant. Hope was there for he had passed all medical testing, yet another denial came. Now it was ICU/PICU saying they wouldn't treat him post-transplant because of a risk of behavior. His doctor came up with a plan if a behavior was to happen, she would put an order for extra sedation. All teams of heart, kidney and brain agreed this would be safe. However, ICU/PICU would still not approve, with no ICU/PICU, transplant could not happen at the Mayo. His doctor cried with us in the room stating that she would help me get him into another hospital telling me there are states that have laws to protect Bryce, and that this is because of his autism, but he does not have the time to keep fighting appeals here.

Now onto our next fight, as we have tried all hospitals in our home state that do liver transplants, and Bryce's time was running out he was getting sicker, I knew he did not have the time for me to keep appealing. I began looking for his life saving chance, within the next week I had contacted every transplant hospital in the United States that had laws to protect those with disabilities, and had appointments scheduled with everyone. Our doctor with the Mayo personally sent over all his information and also talked with every hospital about Bryce.

Bryce's first appointment was with Cincinnati Children's Hospital in Ohio. It was at this time that we got a call from his MN doctor with the Mayo saying that she would only be with the Mayo for two more weeks. She stated that she can no longer work for a hospital that has such discrimination. I can't say for sure if it was because of Bryce, but only one can assume it played a role.

Now we are off to Ohio. For our first appointment Bryce's first time out of state and 13 hours away from our family and home. We got there and did labs and met with the doctor and coordinator just like the two times before with the Minnesota transplant hospital. We were told to go home and pack up for three weeks so he could meet all of the doctors and get approval that he could medically handle a transplant. So within a week we were back in Ohio to start his testing. Once more Bryce passed all his testing. We had our final appointment at CCH who agreed he needs a transplant soon as he is dying from liver failure and it will only get worse if he does not get a transplant. It was the simple words yet the biggest words "We are going to help him and get him listed. We meet next week. I will present him to the board and then we will list him once approved." I was in shocked with how smoothly it went. I clearly remember saying "You know he has autism right?" After being shocked with that question they replied "Yes but that doesn't matter. It won't make the transplant any more or less effective." So we went home for a week of sitting on egg shells, holding out hope that this was our last stop. Knowing we have been in this spot two times before we had to be prepared not to be crushed and keep on fighting. That week came along with the phone call, two hours early, with great news: "Bryce has been approved and will be listed once insurance gives us the approval which should only take 24 to 48 hours." We could finally breathe. Although it was not 24 to 48 hours for Bryce's approval. It was another four months for the approval from Minnesota's insurance for out of state transplant with lots of work from me and the doctor proving that there was no choice, Minnesota would not do the transplant and he needed a transplant in order to live.

October 2019, we heard the harsh truth during his appointment that Bryce was too sick to be that far away. We would have to relocate to Ohio for his health. With it being just the kids and I and how much Bryce was in and

out of the hospital this left no choice but to leave my two other children back in Minnesota with my parents for a unknown amount of time.

September 4, 2020 at 9:30 p.m. we received the call they had a match. Bryce's transplant was completed early morning on September 5, 2020. The surgeon came and told me that he had no explanation how Bryce was not in the hospital full time already and that his body was shutting down and he wouldn't have made it passed December. Bryce remained in sedation like the Mayo doctor had recommended until it was safe for the drain tubes to come out and that they were sure the bleeding was able to clot. Bryce was back to his happy self within two minutes of his sedation medication being removed. Bryce was up and out of bed signing for the bathroom. Within a few hours he was eating and trying to talk. His voice was weak, but he was talking with words that had been taken away for almost two years because of his ammonia levels getting so high his brain could no longer concentrate enough for him to be able to get anything out in order. Bryce was able to leave the hospital and be back home in a little less than two months. Bryce was back into school in a little under five months post-transplant. He is now laughing and enjoying life with his family and friends. The hospital and all staff have stated so many times how well he has done on all levels, behavior and medically, and how they have learned so much from him to help other children like him.

Bryce's strength has been nothing short of amazing. He is a true example of overcoming discrimination and not giving up hope when so many gave up hope with him. He even rocked an appointment with his first liver doctor at children's hospital who thought he couldn't handle a transplant. This same doctor made the choice after that appointment that she would no longer be willing to treat Bryce for post-transplant follow up care. This now results in us going back to Ohio monthly for follow up care.

We tell Bryce's story not for pity not for shame onto our hospitals in Minnesota because we do have wonderful hospitals that have performed many miracles. We tell his story not only to open others' eyes of this issue, but in hopes that our family will not be going down this same road if Eric's health follows the same path. Also, so that no other family has this sort of pain or struggle. There is absolutely no reason why our family had to spend almost two years apart for something that could have been done two or four hours away from our home. Our family understands that every day is a gift and Bryce is living on a gift from a stranger's generosity of being a donor.

Thank you,

Nikki Golden

