

Chairman Lipps, Vice Chair Holmes, Ranking Member Russo, and Members of the House Health Committee, thank you for the opportunity to provide proponent testimony on House Bill 248.

My name is Erica Ryan and I am Project Manager, a wife and mom of 4 boys 12 and under. The reason I support House Bill 248 is because I want to ensure INFORMED CONSENT and right to CHOOSE is given for any and all medical procedures and pharmaceutical products.

For the last 3.5 years my husband and I have been ingrained into the medical community from a caregiver standpoint. Our youngest son, Westley- age 3, spent 100% of his life being supported in some fashion by medical equipment, pharmaceutical products and medical procedures. 535 of his 1150 days on earth (which is 46.5% of his life) were spent living in a hospital. While we are grateful for the equipment, pharmaceuticals and procedures, we were even more grateful to be allowed a CHOICE and to contest when needed, to effectively advocate for our son.

While my husband and I immersed ourselves in all aspects of understanding exactly what was happening, we found through trials and dark times that the medical community is limited in full understanding of why some things happen and the treatments provided can do more harm than good (which is why they are called PRACTICING physicians). Every day they continue to learn and grow in their knowledge, even if they are listed as "experts". We, his parents, were the only people who cared for our son consistently, and understood trends in his specific care on a day-to-day basis. Due to our understanding of our son's health issues, we were able to avoid pitfalls that would have cost our son his life.

As an example, a medication that works extremely successfully in the majority of Heart patients and for which the benefits outweigh the risks for 99% of the population, caused frequent fevers for our son and eventually led to loss of 2/3 of his intestines due to not identifying Necrotizing Enterocolitis soon enough, because we had been told to disregard fevers (the "rare" side effect) unless he got over 103 degrees or became lethargic. From that day forward we became empowered advocates who questioned every procedure, every medication and every piece of material that went into his body because, while they may be experts in their specialty, when you are working with MULTIPLE specialties, WE were the only ones tying all the pieces together and were experts in our son. We wanted to understand the pros and cons of everything and have FULL UNDERSTANDING before we would agree to something. We appreciated that they listened to us after we all consulted together, and we always came to a mutual conclusion what was best for him.

After getting sepsis and a fever of over 107 for a THIRD time, a medication was given to our son during an extreme circumstance that is used to treat rapid declines to prevent coding; however, for him, caused a quicker spiral which then led us to a 1 month stay in the ICU in order to repair the damage the medication caused. Time and time again, we found that our son was the "rare" the "1%" and there always was an extreme caution by everyone because we didn't know how HIS body would react to certain things. While on paper our child was the "outlier, the rare or the 1%" in the majority of treatments and medication, to his parents who it impacts 100% of our day-to-day lives; it doesn't feel "rare". Even one extreme case of side effect can create more than that 1 life that is forever changed.

In August 2019 when we were told there was "nothing else we can do" and that he would be "comatose" the rest of his life we CHOSE to take him home to enjoy quality time over quantity. While home, AGAINST MEDICAL ADVISE, we withdrew a medication we felt was creating more issues and

causing more harm than good. We were provided with INFORMED CONSENT AND CHOICE and had to agree with the physician that we understood that removing the drug could cause him to seize and die. They then provided a wean schedule for us to follow. What happened after we removed this medication? He THRIVED! He became responsive, starting to hit milestones, improving in EVERY area of development and engaged with us and his brothers. He had a personality again and never did he seize or have ramifications of that drug removal. Had we not had a CHOICE he would have continued to be comatose the rest of his life. As well, even after CHOOSING something different for our own son, we did not get kickback or change in care when he would get sick. I fear that not supporting this legislation would set precedent and create a slippery slope as to what other CHOICES turn into MANDATES for how to care for myself or my children. As well it can create SEGREGATION and prioritizing who “deserves” care based on decisions of a person. Had we had a seizure I currently know that a hospital would have helped us, not declined services based on the removal of the medication. I do not know that it would be the case if MANDATES are allowed thus creating a secondary class of citizens based on personal medical decisions.

Our sweet Westley passed away this April due to long term organ damage due to medications and many procedures. While Total Parenteral Nutrition (or TPN for short) is lifesaving, the long-term usage can be deadly. We pushed to get him off it as quickly as possible and we were met with several challenges along the way. In the end it was our CHOICE to push this removal which we FULLY believe, and physicians who interacted with him afterwards fully believe, gave him extra time on Earth with us as a happy child and allowed him to attend school, therapies and interact in the community because we were also able to remove his direct IV line to his heart.

I feel it's important to recognize that we are grateful for all the lifesaving and life-giving ways that medical technology, pharmaceuticals and procedures have given us thus far. I also recognize that other parents/caregivers may have made CHOICES different from us in similar circumstances and I fully respect their CHOICE. I recognize the importance of each of these and want to ensure individuals and caregivers/parents get to make CHOICES for what is best for them by being FULLY INFORMED to full information, including long term side effects and risks, and have the CHOICE to decide what is best for their situation and body. I fear that MANDATES for any procedure or pharmaceutical could set precedent to later mandate other items that those not involved in the direct care for an individual could impose. If no FULL INFORMATION can be given in any situation, including a FULL list of ingredients and all LONG-TERM SIDE EFFECTS or effectiveness, then not one person has given INFORMED CONSENT. By not giving a CHOICE to an individual you are stripping away their freedom to care for their body in the way that they, their caregivers or their medical team best see fit in their circumstance.

I support HB 248 on behalf of myself, my husband, my 3 Earthly boys and in memory of our sweet Westley where we were free to get INFORMED CONSENT and CHOICE in all his care.

Thank you once again for this opportunity to provide testimony on the need for and urgency of House Bill 248.

Sincerely-

Erica Ryan