

Senate Health Care and Human Services Committee
Tonia Whisman, Stayton, OR
February 14th, 2013

Testimony Submitted in support of SB 172

Chair Monnes-Anderson, members of the committee, hello my name is Tonia Whisman and I am here today on behalf of my daughter Rachel. She was born with a heart defect which left her with no functioning left ventricle. Unlike most babies with her condition, she was not diagnosed via ultra sound prior to birth. We raised concerns about her symptoms while in the hospital but were told they were in the range of "normal". We took her home but found ourselves back in the ER less than 24 hours later with a baby who was only minutes from taking her last breath. Herculean efforts were made to stabilize and then Lifeflight her to Doernbecher Children's Hospital. She suffered massive injuries to her vital organs due to oxygen deprivation. Most who treated her that day expected that she wouldn't survive the night but she, in fact, did and began the difficult 7-day battle in the ICU to recover enough.....not to go home but to be stable enough to endure open-heart surgery.

A simple pulse-ox test wouldn't have changed her defect or the need for surgery but it would have caused her to receive the treatment she desperately needed the **day** she was born. She would have been made comfortable and allowed to prepare for the first of what would be a 3-stage surgery process. Instead the first four days of her life were spent being slowly suffocated. A newborn's first experiences should be filled with love and tranquility and while we did love and nurture her, I have to wonder if that was overshadowed by the pain of her body slowly shutting down. The fact is she started dying the moment she started breathing and one little test could possibly have drastically changed her life. The lack of an early diagnosis complicated her recovery both before and after surgery. This increased the length of her hospital stay and the amount of her bills. It also left her with some permanent brain damage which has led to epilepsy and some learning and behavioral disabilities. I am blessed beyond measure to tell you that she is one of the lucky ones. That despite all these obstacles and a long, hard fight, she is now a precocious, curious, exhausting, entertaining, compassionate and joyful 11-year old. We don't know how long her heart will function adequately in its current state but view every day as a gift.

I had hoped to introduce her to you today but she emphatically informed me she had much better things to do, namely her class Valentine's Day party. And so I am here, advocating for her and others like her who simply ask for a fair chance. If they must battle the monster that is heart disease, they only ask that we provide every weapon, every resource, every opportunity for them to not only survive, but to thrive. Because the truth of the matter is, ladies and gentlemen, there are approximately six babies born every week in Oregon with some form of CHD. Chances are a family's life has been forever changed today, possibly only a few miles from here. Whose will it be tomorrow? One of you? Your family? Your friend? I've heard people say, "If I can keep just ONE person from going through what I did, then my efforts were worthwhile".....well frankly, that's not good enough. We can do better. Someone once said that "Knowledge is power" but a man named Dale Carnegie said, "Knowledge isn't power until it's applied". What does it say about us if we fail to apply our knowledge to prevent what happened to Rachel from continuing to happen? Who among us can look at them and say, "it's not worth a try"? Please join us in our support of Senate Bill 172. We can give these kids the best chance possible to be all they were meant to be. Thank you for your consideration.

Thank you,

Tonia Whisman