

I am writing to respectfully ask you to support this important bill [HB1112](#) / [SB891](#) entitled Public Health - Maternal and Child Mortality - Review and Perinatal Hospice Services.

I believe that this bill would be very beneficial to other families and parents who find themselves being faced with the unfortunate reality of carrying a baby that has been given a fatal prenatal diagnosis. This is the situation I experienced five years ago when I was pregnant with my first daughter, Ember Marie.

At 19 weeks pregnant when I went for my anatomy scan we received the unfortunate news that our daughter had a fatal prenatal diagnosis called bilateral renal agenesis. At this time we were not provided much information other than that I would likely not carry to term as this is incompatible with life.

Hoping this information was incorrect I contacted all the local hospitals and each doctor informed us the same thing, they were unable to locate kidneys or get clear images due to lack of amniotic fluid. The lack of amniotic fluid prevents proper lung development which ultimately results in the death of the baby. I was advised by the head of fetal and maternal medicine at one major hospital that I would be risking my ability to have children in the future if I did not “induce early” and that it would be best to just move on and try and get pregnant again. Another major hospital told me that they did not understand why I had not miscarried in the first trimester and that I would lose her any day. We left these hospitals feeling hopeless and discouraged.

After my follow up scan at St. Agnes my regular OBGYN met with us and provided us with a pamphlet for Isaiah’s Promise. My OBGYN was familiar with Isaiah’s Promise and shared her knowledge of how other mothers had been able to find strength, support and joy throughout their pregnancy thanks to being linked with mothers who had similar experiences. My OBGYN was the only one to provide me with this resource and encourage me to continue my pregnancy.

The mothers I was connected with through Isaiah’s Promise shared with me their experiences from receiving the diagnosis to delivering and cherishing their baby. I was encouraged to make the most of every moment pregnant with my daughter and provided with priceless keepsakes such as a handmade

baby blanket, mommy and me bracelets, and a necklace that her father still wears every day. Isaiah's Promise was available any time I needed additional support or had questions regarding what I needed to do to prepare for my daughter's birth and death. We were provided with resources on birth plans, local funeral homes, the Trappist Monks (who donated our daughter's casket), and local photographers linked to Now I Lay Me Down to Sleep. Through the support of these amazing mothers we were able to make the most of a heartbreaking situation and chose to celebrate my daughter every chance we could. In spite of what every medical professional had predicted Ember Marie was born alive on May 31<sup>st</sup> 2016 at 37 weeks and we were able to hold her for all of her short life. Thanks to the recommendations from Isaiah's Promise her father was able to read to her, bathe her and dress her. We were able to have our closest family and friends present as well as the photographer from Now I Lay Me Down to Sleep who was able to capture our first and last moments with Ember Marie. One of the mothers from Isaiah's Promise even came to the hospital and assisted with making hand and footprint molds. I am forever grateful for the support and encouragement I received from Isaiah's Promise that allowed me to treasure and honor my daughter rather than never getting the chance to hold her or meet her. They have continued to support me through the years and most recently with my second pregnancy and birth of Ember Marie's little sister. Without being provided with this resource I never would have known that it was possible to find joy in such a hard situation and I hope that other mothers will be given this same opportunity through Perinatal Hospice Services.

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