

Support for HB1112, Providing Information on Perinatal Hospice

Honorable Members of the Health and Government Operations Committee, we write to you as parents who have participated in a Maryland perinatal hospice program to urge your support for HB1112.

In the fall of 2012, while 19 weeks pregnant with our second child Joseph Angelo at a routine sonogram, we received the devastating diagnosis of Thanatophoric Dysplasia for our son along with the news that he was not expected to live past birth. Presented with all our options at the time, we chose to continue the pregnancy. We felt that if he was to die, it would not be because of a decision we made and we chose to let nature take its course. We were supported in this decision by an exceptional multidisciplinary team of medical professionals and we participated in Gilchrist Hospice Care as well as Isaiah's Promise, a parent led support group who walked with us on this meaningful and healing journey.

Joseph was born on December 13, 2012 and he lived just an hour after his birth. Because we were prepared and had excellent care, his birthday was a day of not only mourning, but also a day to celebrate the gift of life. We are so thankful to our medical and perinatal hospice team who respected our wishes and allowed us to experience both the joy and pain of saying hello and goodbye to our son, preparing us for death and life at the same time. We have no regrets. We view Joseph's life as a blessing that truly shaped our family and our life today over eight years later.

Since 2013, I (Jenny) have volunteered for Isaiah's Promise, a program that provides parent to parent support to families who choose to carry to term after receiving a life-limiting diagnosis and accompanying them in this difficult yet precious time. Through the years, it saddens me to hear so many stories of other parents who did not receive medical care that respected their wishes, those who were only offered termination, and those who felt alone in their choice and struggled to find resources and a network of support. No parent should feel pressured in a moment of crisis to make an immediate and final decision for their child without all the options presented.

Providing doctors and parents with information on perinatal hospice through brochures and the Health Department website will allow for an improved standard of care in Maryland for these parents. This will increase opportunities for informed decisions and improve parent research following the initial diagnostic appointment when devastated and overwhelmed parents leave the hospital searching for support. For these reasons, we urge a favorable report on HB1112.

Thank you for your time, consideration and your service to our community.

Respectfully,

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For additional information on the Mohler's story and Gilchrist Hospice Care see the attached Baltimore Sun story

