

March 16, 2021

Health and Government Operations Committee, Maryland General Assembly

Re: Testimony in support of HB1112

Dear Honorable Members of the Maryland Senate,

I am writing this letter to share our family's personal experiences in receiving perinatal hospice care and support and how the need for this information and resource is of great importance to a family who receives that awful news and diagnosis. What should be their happy parent moment at their ultrasound appointment turns into a devastating shock. Our family has had the fortune and the unfortunate experience of two such fatal diagnosis and having to bury two children.

We have two healthy children who were ecstatic to bring a new baby into our family. We were told at 11 weeks, January 2016, that the DNA test showed we were having a boy and that Trisomy 18 was evident. We held hope until week 13 for his ultra sound yet his measurements and pictures only confirmed the bloodwork results. We were nervous, scared, and counseled that it would be the best to terminate. I remember asking questions about if our baby would survive to term and wanting to know about other options but not given much information or hope.

We were completely blown away and went home devastated. We are a Christian family though Lutheran, we do not abide by any strict demands regarding abortions. When it came down to it, my husband and I decided this was a child we wanted, planned for, and rejoiced at his positive pregnancy test. (I had a miscarriage at 8 weeks in the previous fall). I am in special education and down to the core it just did not feel ethical to end a life just because it was going to have severe needs, if even able to live past birth. My husband and I shared our commitment to our son when the genetic counselor called us back the following day.

As luck would have it, a new genetic counselor had come to the practice that we weren't able to meet with the day of our diagnosis. She was previously from Annapolis where she said families don't seem as pressured to terminate and choose to carry forth difficult pregnancies. She explained of a resource in Annapolis who ran a prenatal hospice program for parents. I never knew of such a thing. Our OBGYN was connected to Holy Cross Hospital (Catholic) which had such a program and our genetic counselor put us into contact with the nurse in charge. She arranged a meeting with us, the diagnosing doctor and the nurse in charge of the 'Never Alone' program. A program that tries to meet the medical and emotional needs of families birthing babies such as our son.

The meeting helped chip away at the mountain of questions we had and we received another program reference to Isaiah's Promise. They assign a mentor (a mother who has experienced a severe diagnosis and loss) to follow the mother and family through the *entire* pregnancy. The mentors help us plan the birth arrangements (and funeral if need be), make remembrances along the way and during birth, and remember important days for the family for the following two plus years after the child's birth/or loss.

For the first time in my life, I truly feel that I know the "Grace" of God and know that I have experienced it first-hand. I don't know how we would have weathered Joseph's birth and death if we had not stumbled upon that new genetic counselor who just started at our specialist practice. Her tiny knowledge of perinatal hospice care opened so many more avenues of support. Imagine our horror when a year later at 5 months pregnant with our first girl, we were told at an appointment at Children's that our daughter had a rare form of dysplasia and would likely not live past a day. I tell my sponsor from Isaiah's Promise that there is no way our family could have survived that second tragic loss without the support of their program and just as important the Never Alone program at Holy Cross Hospital.



I am coming to the end of my one-page testimony. I humbly ask to share a snapshot in the year of 2016 and 2017 of our family by enclosing the attached documents. The enclosures are communications we shared with our close friends and family; Joseph's, dated October 21, 2016 and Alaina's September 11, 2017.

Thank you for listening to our family's journey of joy and pain and allowing us to share our two precious children with you. Please, do support more information and resources for families such as ours who want to love and support their own children 'as far as they will go'.

Respectfully,

*Mrs. Katherine M. Fitzgerald*



Mrs. Katherine M. Fitzgerald of Aspen Hill, Maryland

Enclosure

Alaina Elizabeth Fitzgerald Born & Baptized November 30, 2017 Died December 2, 2017 in parents arms



Joseph Harold Fitzgerald, Born & Baptized September 15, 2016 Died October 9, 2016 at home with family

