

**TESTIMONY OF MARY H. PEROUTKA to the
HOUSE GOVERNMENT OPERATIONS COMMITTEE of the
MARYLAND HOUSE OF DELEGATES
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My name is Mary Peroutka, and I have been a Labor and Delivery Registered Nurse for forty years.

I want to start with “What is *hospice*?” For many, that word invokes thoughts of death, dying, pain, and ending. But hospice is really about life. The goal of hospice is to enable patients and families to live their best lives possible, as pain-free as possible, and for as long as possible.

Now we add another word to go with *hospice*, and that is *perinatal*. The word *perinatal* refers to the period of time from about the twentieth week of pregnancy--roughly halfway--through the first weeks of a newborn’s life.

Perinatal Hospice is a concept that has been around for about twenty-five years. It takes the best of perinatal care and marries it with the best of hospice ideals. But who needs it? Any family that has received a diagnosis of a life-limiting condition for a child yet to be born or a newly born child can benefit from Perinatal Hospice. Perinatal Hospice professionals support families as they make choices and decisions for the future of their baby and family. Perinatal Hospice is a multidisciplinary approach that aims to guide through and walk with families during a difficult time.

I started the first Perinatal Hospice program in Maryland about fifteen years ago because there was a need. I have been a Perinatal Bereavement Nurse since 1996. My focus was on walking the journey of healing and remembering and memorializing a life lost

too soon to miscarriage, stillbirth, or newborn death. One day, I was asked to support a family who knew their baby would die soon after birth, but wanted as much time as possible with their baby. As I said, Perinatal Hospice is about life. It is about cherishing each moment, it is about doing all of the things you planned to do with your baby, and doing it now, not later.

As Megan, the mother of this family told me, “We celebrated every day she was with us. We embraced every moment. Things I would not normally do while pregnant, I did with Rosie [her unborn daughter]. We went skiing, roller skating, went down water slides, to name a few things. I took pictures all of the time of our entire family and made a note that we were a family of five. We spoke to Rosie every chance we could get and I made sure to enjoy every kick and movement. I spoke about her often as she was here and living.”

Perinatal Hospice is about celebrating life for as long as it is present, creating memories that will last a lifetime, and setting parents on a journey to healing grief and loss. Because there is no shortcut through grief.

When an anomaly or life-limiting condition is discovered during testing or ultrasonography, we are reminded that our ability to diagnose surpasses our ability to treat or cure. Please remember that not giving patients options is not giving them a choice. Families for whom termination is not the right choice deserve the same supportive information and referral to care. It allows the family the time to decide just what is most important for the short time they will have with this new family member. Families who choose Perinatal Hospice choose a love story, not a tragic journey.

Our society doesn't like to think about death, and it is even more difficult to think about the death of children. If any of you have been in the position of deciding the future of a difficult pregnancy, you understand all the dilemmas. But if you have never lived this situation, I ask you to withhold judgement. Many times, our patients find that their own compassion causes them to make different choices than they expected. Medicine can't treat everything; sometimes, the JOURNEY is the treatment.

I urge a favorable report on House Bill 1112. Thank you for the opportunity.

Here are some resources that can provide more information:

- "Perinatal Hospice Video"; Available online at <https://www.youtube.com/watch?v=rTTNeqRvZ3w&t=1s>
- "Perinatal Hospice: Continuing Your Pregnancy When Your Baby's Life Is Expected to Be Brief"; Available online at <https://www.youtube.com/watch?v=tY7mq1g9pGk>
- *Waiting with Gabriel: A Story of Cherishing a Baby's Brief Life* by Amy Kuebelbeck. 2008. Available at <https://www.amazon.com/Waiting-Gabriel-Story-Cherishing-Babys/dp/0829428569>
- *A Gift of Time: Continuing Your Pregnancy When Your Baby's Life Is Expected to Be Brief*. 2011. Available at <https://www.amazon.com/Gift-Time-Continuing-Pregnancy-Expected/dp/0801897629>