

SB891

Letter of Information

TO: The Honorable Delores Kelly
Chair, Senate Finance Committee

FROM: Renee D. Boss, M.D., M.H.S.
3212 Juneau Place
Baltimore, MD 21214

DATE: March 10, 2021

My name is Dr. Renee Boss and I am an Associate Professor in the Department of Pediatrics at the Johns Hopkins School of Medicine and Director of Pediatric Palliative Care at the Johns Hopkins Children's Center. I am an international expert in serious fetal and neonatal illnesses, with a focus on providing young parents and families with the services needed to support grief and bereavement. I am concerned that Senate Bill 891 will mislead families and potentially limit their access to available resources in our community. I submit this testimony as a physician and concerned resident of Maryland. I am not representing the view or position of the Johns Hopkins University or School of Medicine.

SB891 addresses the case where a pregnant woman receives the diagnosis of a fetal condition likely to result in the infant death. SB891 advocates that the Department of Health create website information and a printed information sheet about "perinatal hospice services." SB891 states that inclusion of a perinatal program in the website/ information sheet will occur via request by the perinatal program, with no requirement for or system to evaluate the program's licensing or credentialing.

Palliative care is highly specialized medical care provided by a trained team of clinicians. This team includes medical personnel, counselors and spiritual care providers who treat children with serious illness via a combination of medical and emotional supports. Pediatric palliative care teams are trained to support the families of these children, often helping them make difficult medical decisions.

Hospice is a discreet element of palliative care that focuses on the final months of life. Hospices are licensed, credentialed inpatient and outpatient facilities certified to care for dying patients. Hospices are required to provide 24/7 access to medicines and interventions delivered by medical personnel. Hospices also have highly trained teams of psychological and spiritual professionals to support the entire family at the end of life and during bereavement. These specialized family supports can begin before birth, in the case of a prenatal diagnosis.

While SB891 use the term "hospice," there is no evidence that the programs to be included on the website/ information sheet will meet the professional or legal standards of hospice care as delivered by trained medical professionals. Parents may therefore be misinformed about the quality of those programs, with potential impact on the medical decisions they make for their child.

I am very concerned that SB891 would hinder parent and child access to high quality, licensed palliative care and hospice services.