

REGIONAL HOSPICE

Testimony of ToniAnn Marchione, President and CEO of Regional Hospice, Co-Chair of the Task Force to Study Pediatric Hospice in the State

Good afternoon, Representative McCarthy Vahey, Senator Anwar, and distinguished members of the Public Health Committee. My name is ToniAnn Marchione, and I am the President and CEO of Regional Hospice, as well as the co-chair of the appointed task force to study pediatric hospice in our state.

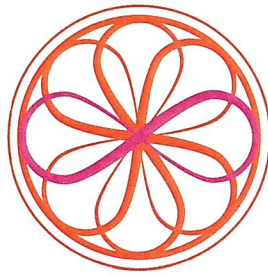
I am grateful for the opportunity to speak before you today to share the findings of our task force and the critical barriers we have identified that hinder the creation of a seamless pediatric hospice program. Our work has been driven by one simple, yet profound goal: to ensure that children facing life-limiting illnesses and their families have access to the care, support, and dignity they deserve during this incredibly challenging time.

One of the most pressing challenges we have identified is the need to pilot a **Center of Excellence** dedicated to the education of nurses in pediatric hospice and palliative care. Nurses are the heart of hospice care, and their specialized knowledge in pediatric care is essential. Currently, there is a lack of comprehensive training programs focused specifically on the unique needs of children, which creates a significant gap in the quality of care provided. A Center of Excellence would provide critical, focused education and clinical training to ensure that nurses are equipped to deliver the best possible care to children in need.

Another key barrier we have found is the need for better education and awareness for **referring physicians** regarding **concurrent care**. Many physicians are unaware that children in need of hospice care may also continue to receive curative treatment concurrently. This misunderstanding often results in delays or missed opportunities to refer children and families to hospice care at the appropriate time. A more robust educational initiative is needed to equip our medical community with the knowledge and confidence to make timely, compassionate referrals.

Additionally, we have found a lack of consistent communication with parents about **palliative and hospice options**. Many families are not fully aware of the full scope of pediatric hospice services, and there is often confusion and fear around what hospice care entails. Clear, consistent messaging is crucial to ensuring that families can make informed decisions about their child's care without fear or misunderstanding.

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Our task force also recommends the creation of a **generalized program** that provides palliative and hospice care across all levels. This would help create a more accessible, inclusive system that meets the needs of all families, regardless of the complexity of their child's condition or where they are in their care journey. A program that not only sets the standards and criteria for all providers licensed in this state to provide hospice care but helps to monitor the needs of each case.

In conclusion, the task force is requesting **additional time** to further develop a **pilot program** and conduct additional research into successful models from other states that have effectively implemented pediatric hospice programs. Our goal is to ensure that we design a program that is thoughtful, comprehensive, and ultimately provides the best care for our children and their families.

Thank you for your time and attention. We are committed to working with all of you to make this vision a reality and to ensure that every child in our state has access to the care and dignity they deserve.