



**Proponent Testimony - House Bill 286**  
**House Aging and Long Term Care Committee**  
**Dr. Sarah Friebert, M.D.**  
**Akron Children's Hospital**  
**Tuesday, October 3, 2017**

Chairman Arndt, Vice-Chair Pelanda, Ranking Member Howse and members of the House Aging and Long Term Care Committee, my name is Dr. Sarah Friebert, and I am the Director of Pediatric Palliative Care at the Haslinger Family Pediatric Palliative Care Center at Akron Children's Hospital. Thank you for the opportunity to offer proponent testimony on House Bill 286, which would create the Palliative Care and Quality of Life Interdisciplinary Council and establish the Palliative Care Consumer and Professional Information and Education Program.

Akron Children's Haslinger Family Pediatric Palliative Care Center provides care to children, prenatal to young adult, with complex, chronic or serious conditions and their families, enhancing quality of life in partnership with cure-directed care. Our mission is to integrate indispensable and individualized pediatric palliative care into the journey for all children, adults and their families living with chronic, complex and/or life-threatening conditions of childhood. As one of the largest pediatric palliative care programs in the US, we have been serving children and families since 2002, and our program was the first pediatric program to be certified in palliative care by the Joint Commission.

Additionally, we strive to provide leadership in education, research and advocacy initiatives in pediatric palliative care locally, regionally, nationally and internationally. We were honored to work with State Representative Sarah LaTourette, as well as many other provider and advocacy groups, over the last several months in a thorough interested party process to develop the provisions of HB 286. We appreciate State Representative LaTourette's passion in advancing this initiative, and specifically, her willingness to include components of palliative care as it relates to pediatrics, which can be very different from adult palliative care, as part of this bill.

When a child faces a chronic condition or a serious illness, families often feel as if life has become a roller coaster ride, and we are here to provide support along the journey, no matter what the outcome may be. Pediatric palliative care focuses on infants (even prenatal), children, adolescents and young adults with complex or chronic conditions and their families, from the time of diagnosis until cure (if that is possible) or through the bereavement process for those who do not survive. Palliative care and curative care are not either/or. In fact, palliative care is most beneficial and effective for families when it is offered and delivered concurrently with disease-modifying therapy.

Our approach focuses on controlling pain and other symptoms, as well as addressing psychosocial, emotional, practical, spiritual, educational and developmental issues, which may contribute to suffering or interfere with healing. Palliative care is truly the effort of a transdisciplinary team, including, but not limited to: physicians, nurses, social workers, case managers, bereavement specialists, chaplains, child life specialists, pharmacists, psychologists, volunteers, and rehabilitation and expressive therapists.



Most people think that palliative and hospice care are reserved for end of life or only after a terminal diagnosis, but palliative care actually is most effective if it's made available as soon as a serious or life-threatening illness is diagnosed. In fact, palliative care is appropriate at any stage of the illness. Further, various studies and multiple clinical trials have demonstrated that early palliative care intervention and care can dramatically improve outcomes, increase patient and provider satisfaction, and significantly reduce costs.

Our palliative care team at Akron Children's prefers to be involved as early as possible. This is helpful for many reasons. It allows us to get to know the patient and family, and be better aware of their goals and wishes throughout the illness. If many different specialists are involved, we can help coordinate care and communicate across transitions. We focus on allowing children to be children first, remaining at home, in school, and involved in their families and communities as much as possible. Our team works in collaboration with a child's other health care providers and specialists, helping to provide seamless care coordination and communication, and assisting families in making informed choices about difficult medical decisions. We deliver care to patients and families where they feel most comfortable, whether in a home, clinic, hospital or alternative setting. Palliative care efforts are completely compatible with the pursuit of interventions directed at prolonging life, and treatment is customized to meet the needs of each individual patient.

I'm offering my support to HB 286 because, unfortunately, palliative care services are underutilized in the state of Ohio, representing missed opportunities to improve quality of life for patients and their families. The creation of the Palliative Care Council is a solid step forward to further integrate palliative care into the landscape of treatment for those facing serious illnesses. This council will be comprised of those with substantive knowledge of palliative care and represents a wide-range of providers – similar to the team approach that makes palliative care treatment successful. In an advisory role to the Ohio Director of Health, the Palliative Care Council will be a valuable asset to the Ohio Department of Health as palliative care programs become more widespread across a variety of medical facilities and care settings.

House Bill 286 will also establish the Palliative Care Consumer and Professional Information and Education Program. Like the Palliative Care Council, this program is an important step forward in palliative care information and education; it would serve to make substantive, comprehensive and accurate information and education on palliative care available to patients and their families, as well as to providers and medical facilities.

Chairman Arndt and members of this committee, thank you for taking the time to read my proponent testimony. I support HB 286, and I hope to see it advance into law in this General Assembly. I am, respectfully, asking for your support.