1 AN ACT relating to patient quality of life. 2 Be it enacted by the General Assembly of the Commonwealth of Kentucky: 3 → SECTION 1. A NEW SECTION OF KRS CHAPTER 211 IS CREATED TO 4 **READ AS FOLLOWS:** 5 As used in Sections 1 to 3 of this Act: 6 "Cabinet" means the Cabinet for Health and Family Services; (1) 7 (2)"Council" means the Palliative Care Interdisciplinary Advisory Council 8 established under Section 2 of this Act; 9 (3) "Health facility" has the same meaning as in KRS 216B.015: "Medical care" means services provided, requested, or supervised by a physician 10 (4) 11 licensed pursuant to KRS Chapter 311 or advanced practice registered nurse 12 licensed pursuant to KRS Chapter 314; "Palliative care" means patient- and family-centered medical care that 13 (5) 14 anticipates, prevents, and treats suffering caused by serious illness and involves 15 addressing the physical, emotional, social, and spiritual needs of a patient and 16 facilitating patient autonomy, access to information, and choice. Causing or 17 hastening death shall not be deemed a method for anticipating, preventing, or treating suffering as described in this subsection; and 18 19 (6) "Serious illness" means any medical illness, physical injury, or condition that 20 causes substantial suffering for more than a short period of time, including but 21 not limited to Alzheimer's disease and related dementias, lung disease, cancer, or 22 heart, renal, or liver failure. → SECTION 2. A NEW SECTION OF KRS CHAPTER 211 IS CREATED TO 23 24 **READ AS FOLLOWS:** (1) The Palliative Care Interdisciplinary Advisory Council is hereby established to 25 improve the quality and delivery of patient- and family-centered care throughout 26 27 the Commonwealth and to advise the cabinet on matters related to the

1		establishment, maintenance, operation, and outcomes evaluation of palliative
2		care initiatives. The council shall be attached to and administered by the cabinet.
3	<u>(2)</u>	The Governor shall appoint the members of the council to serve three (3) year
4		terms. The council shall consist of thirteen (13) voting members, and may include
5		nonvoting members who are relevant cabinet representatives designated by the
6		Governor. Voting members shall be:
7		(a) Two (2) members from interdisciplinary medical, nursing, social work,
8		pharmacy, and spiritual professions with palliative care work experience or
9		<u>expertise;</u>
10		(b) Two (2) members who are either licensed or certified hospice and palliative
11		medicine physicians licensed pursuant to KRS Chapter 311 or licensed or
12		certified hospice and palliative care advanced practice registered nurses
13		licensed pursuant to KRS Chapter 314;
14		(c) One (1) member who has pediatric palliative care expertise;
15		(d) One (1) member who is a patient or family caregiver advocate;
16		(e) One (1) member recommended to the Governor by the Statewide
17		Independent Living Council;
18		(f) One (1) member recommended to the Governor by the American Cancer
19		<u>Society;</u>
20		(g) One (1) member recommended to the Governor by the Kentucky Right to
21		Life Association;
22		(h) One (1) member recommended to the Governor by the Long-Term Care
23		<u>Ombudsman Program;</u>
24		(i) One (1) member recommended to the Governor by the Kentucky Association
25		of Hospice and Palliative Care;
26		(j) One (1) member recommended to the Governor by the Kentucky
27		Psychological Association; and

1		(k) One (1) member recommended to the Governor by the Kentucky Association
2		of Health Care Facilities.
3	<u>(3)</u>	Appointed members of the council shall serve without compensation, but shall be
4		reimbursed for actual expenses incurred in the performance of duties in
5		accordance with KRS 45.101 and administrative regulations promulgated
6		thereunder.
7	<u>(4)</u>	(a) Members of the council shall elect a chair and vice chair whose duties shall
8		be established by the council.
9		(b) The time and place for regularly scheduled meetings shall be established by
10		a majority vote of the council, but there shall be at least two (2) meetings
11		<u>per year.</u>
12		(c) The chair or any three (3) voting members shall provide two (2) weeks'
13		notice to the members regarding an upcoming meeting.
14		→SECTION 3. A NEW SECTION OF KRS CHAPTER 211 IS CREATED TO
15	REA	D AS FOLLOWS:
16	<u>(1)</u>	The statewide Palliative Care Consumer and Professional Information and
17		Education Program is hereby established within the cabinet.
18	<u>(2)</u>	The goals of the Palliative Care Consumer and Professional Information and
19		Education Program shall be to maximize the effectiveness of palliative care
20		initiatives throughout the Commonwealth by ensuring that comprehensive and
21		accurate information and education about palliative care are available to the
22		public, health care providers, and health facilities.
23	<u>(3)</u>	The cabinet shall publish on its Web site information and resources, including
24		links to external resources, about palliative care for the public, health care
25		providers, and health facilities. This shall include but not be limited to:
26		(a) Continuing education opportunities for health care providers;
27		(b) Information about palliative care delivery in the home, primary, secondary,

1	and tertiary environments;
2	(c) Best practices for palliative care delivery; and
3	(d) Consumer educational materials and referral information for palliative
4	care, including hospice.
5	(4) (a) The council shall have the authority to review, evaluate, and make
6	recommendations regarding all elements of the Palliative Care Consumer
7	and Professional Information and Education Program, the content of the
8	Web site information and resources described in subsection (3) of this
9	section, and best practices for palliative care delivery and any grants to
10	develop or implement them.
11	(b) Any evaluations or recommendations shall require the affirmative vote in
12	person, by electronic means, or by proxy of three-fourths (3/4) of the voting
13	members of the council.
14	(c) Not later than July 1, 2019, and annually thereafter, the council shall
15	submit a report on its findings and recommendations to the commissioner
16	of the Department for Public Health and to the Interim Joint Committee on
17	Health and Welfare.
18	(5) The Palliative Care Interdisciplinary Advisory Council and the statewide
19	Palliative Care Consumer and Professional Information and Education Program
20	shall cease to exist on July 1, 2028, unless otherwise reauthorized by the General
21	Assembly.
22	→SECTION 4. A NEW SECTION OF KRS CHAPTER 216 IS CREATED TO
23	READ AS FOLLOWS:
24	(1) Any provider of hospice, palliative care, or end-of-life services shall have written
25	policies and procedures for the deactivation or sequestration and disposal of
26	Schedule II, III, IV, or V controlled substances prescribed to a patient when a
27	prescription is discontinued or upon the patient's death by the entity or person

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1		pronouncing the death.
2	<u>(2)</u>	Any provider of hospice, palliative care, or end-of-life services shall provide a
3		copy of the written policy and procedures for the management and the
4		deactivation or sequestration and disposal of Schedule II, III, IV, or V controlled
5		substances prescribed to a patient when a prescription is discontinued or upon
6		the patient's death, to the patient or the patient's legal representative, and the
7		provider shall discuss the policy and procedures with the patient or the patient's
8		legal representative. The patient or the patient's legal representative shall be
9		requested to sign an agreement to this policy.
10	<u>(</u> 3)	In an effort to reduce illegal diversion of Schedule II, III, IV, or V controlled
11		substances, the agreement to the written policy and procedures required under
12		subsection (2) of this section shall inform the patient or the patient's legal
13		representative that if the patient or the patient's legal representative refuses to
14		agree to the deactivation or sequestration and disposal when a prescription is
15		discontinued or upon the death of the patient, local law enforcement or the
16		Department for Public Health shall be notified of the refusal by the hospice,
17		palliative care, or end-of-life services provider or the entity or person
18		pronouncing death.
19	<u>(4)</u>	The deactivation or sequestration and disposal of Schedule II, III, IV, or V
20		controlled substances prescribed to a patient when a prescription is discontinued
21		or upon the patient's death shall be completed by the entity or person
22		pronouncing death and witnessed by an adult. The witness shall sign a statement
23		that he or she witnessed the deactivation or sequestration and disposal.
24	<u>(5)</u>	The deactivation or sequestration and disposal methods of Schedule II, III, IV, or
25		V controlled substances used by the entity or person pronouncing death shall
26		comply with the United States Food and Drug Administration's recommendations
27		for the safe disposal of unused medicines or shall be another safe deactivation or

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sequestration and disposal method.

Section 5. The General Assembly hereby recognizes the extreme pain, suffering,
and anguish experienced by women and families who learn during pregnancy that their
unborn child has a life-limiting condition which could result in the death of the child
before or shortly after birth, or that their child could have a significantly shortened
lifespan related to a terminal condition.

7 → Section 6. The General Assembly hereby recognizes the importance of
8 connecting grieving women and families with perinatal palliative care and hospice
9 practitioners.

Section 7. The General Assembly hereby urges all hospitals and clinics offering obstetric services, obstetric practices, and alternative birthing centers to provide or make referrals for perinatal palliative care and neonatal palliative and hospice care in the instance of a diagnosis that a pregnancy is incompatible with life or that an unborn child has a life-limiting condition that may result in death shortly after birth or a significantly limited life expectancy.

Section 8. The General Assembly hereby urges palliative and hospice care
 providers to establish or expand perinatal palliative and neonatal palliative care and
 hospice programs.

Section 9. The General Assembly hereby urges perinatal palliative and neonatal
 palliative care and hospice providers to provide anticipatory support and counseling to
 patients and families before, during, and after delivery through physical, emotional, and
 spiritual support.

Section 10. The General Assembly hereby urges perinatal palliative and
neonatal palliative care and hospice care providers to include coordination of care
between the obstetric and neonatal care providers, hospital staff, clinic staff, the patient,
and the family of infants with a terminal diagnosis.

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→ Section 11. The General Assembly hereby urges perinatal palliative and

neonatal palliative care and hospice care providers to include assistance with the creation
of a personalized birth plan, designed around the parents' wishes for the labor and
delivery experience and care of their baby at birth, and to assist in the planning of a
memorial service if desired.