- 1 HB194
- 2 191536-2
- 3 By Representative Weaver
- 4 RFD: Health
- 5 First Read: 11-JAN-18

1	ENG	ROSSED
2		
3		
4	А	BILL
5	TO BE	ENTITLED

6 7

8

9

10

11

12

13

14

15

16

17

18

19

20

21

22

23

24

25

26

Relating to terminally ill minors; to amend Sections 22-8A-2 and 22-8A-3, Code of Alabama 1975; to add Sections 22-8A-15 to 22-8A-17, inclusive, to the Code of Alabama 1975; to create the Alex Hoover Act; to authorize the physician of a terminally ill or injured minor to execute, at the request of the minor's parent or legal guardian, a directive for the medical treatment and palliative care to be provided to a terminally ill or injured minor; to require the Department of Public Health, by rule and in conjunction with a task force, to establish a form for an Order for Pediatric Palliative and End of Life (PPEL) Care to be used by medical professionals outlining medical care provided to terminally ill minors in certain circumstances; to provide immunity to health care providers who provide, withhold, or withdraw medical treatment pursuant to an Order for PPEL Care; and to establish a temporary task force to work in consultation with the Department of Public Health to establish an Order for Pediatric Palliative and End of Life (PPEL) Care form. BE IT ENACTED BY THE LEGISLATURE OF ALABAMA:

AN ACT

Section 1. This act shall be known and may be cited as the Alex Hoover Act.

Section 2. Sections 22-8A-2 and 22-8A-3 of the Code of Alabama 1975, are amended to read as follows:

"\$22-8A-2.

3

4

5

6

7

8

9

10

11

12

13

14

15

16

17

18

19

20

21

22

23

24

25

26

"(a) The Legislature finds that competent adult persons have the right to control the decisions relating to the rendering of their own medical care, including, without limitation, the decision to have medical procedures, life-sustaining treatment, and artificially provided nutrition and hydration provided, withheld, or withdrawn in instances of terminal conditions and permanent unconsciousness. In order that the rights of individuals may be respected even after they are no longer able to participate actively in decisions about themselves, the Legislature hereby declares that the laws of this state shall recognize the right of a competent adult person to make a written declaration instructing his or her physician a health care provider to provide, withhold, or withdraw life-sustaining treatment and artificially provided nutrition and hydration or designate by lawful written form a health care proxy to make decisions on behalf of the adult person concerning the providing, withholding, or withdrawing of life-sustaining treatment and artificially provided nutrition and hydration in instances of terminal conditions and permanent unconsciousness. The Legislature further desires to provide for the appointment of surrogate decision-makers in instances where the individual has not made such a designation.

"(b) The Legislature further declares that parents and legal guardians of terminally ill minors have the right to control the decisions relating to the medical and palliative care of their minor child, including, without limitation, the decision to have medical procedures, life-sustaining treatment, and artificially provided nutrition and hydration provided, withheld, or withdrawn.

"(c) and It is the intent of this chapter to allow a health care provider to follow certain portable physician orders for adults and terminally ill minors, as provided for in this chapter.

"\$22-8A-3.

"As used in this chapter, the following terms shall have the following meanings, respectively, unless the context clearly indicates otherwise:

- "(1) ADULT. Any person 19 years of age or over.
- "(2) ARTIFICIALLY PROVIDED NUTRITION AND HYDRATION.

 A medical treatment consisting of the administration of food and water through a tube or intravenous line, where the recipient is not required to chew or swallow voluntarily.

 Artificially provided nutrition and hydration does not include
 - "(3) ADVANCE DIRECTIVE FOR HEALTH CARE. A writing executed in accordance with Section 22-8A-4 which may include

assisted feeding, such as spoon or bottle feeding.

a living will, the appointment of a health care proxy, or both such living will and appointment of a health care proxy.

3

4

5

6

7

8

9

10

11

12

13

14

15

16

17

18

19

20

21

22

23

24

25

26

- "(4) ATTENDING PHYSICIAN. The physician selected by, or assigned to, the patient who has primary responsibility for the treatment and care of the patient.
 - "(5) CARDIOPULMONARY CESSATION. A lack of pulse or respiration.
 - "(6) COMPETENT ADULT. An adult who is alert, capable of understanding a lay description of medical procedures and able to appreciate the consequences of providing, withholding, or withdrawing medical procedures.
 - "(7) DO NOT ATTEMPT RESUSCITATION (DNAR) ORDER. A physician's order that resuscitative measures not be provided to a person under a physician's care in the event the person is found with cardiopulmonary cessation. A do not attempt resuscitation order would include, without limitation, physician orders written as "do not resuscitate," "do not allow resuscitation, " "do not allow resuscitative measures, " "DNAR," "DNR," "allow natural death," or "AND." A do not attempt resuscitation order must be entered with the consent of the person, if the person is competent; or in accordance with instructions in an advance directive if the person is not competent or is no longer able to understand, appreciate, and direct his or her medical treatment and has no hope of regaining that ability; or with the consent of a health care proxy or surrogate functioning under the provisions in this chapter; or instructions by an attorney in fact under a

durable power of attorney that duly grants powers to the attorney in fact to make those decisions described in Section 22-8A-4 (b) (1).

- "(8) HEALTH CARE PROVIDER. A person who is licensed, certified, registered, or otherwise authorized by the law of this state to administer or provide health care in the ordinary course of business or in the practice of a profession.
- "(9) HEALTH CARE PROXY. Any person designated to act on behalf of an individual pursuant to Section 22-8A-4.
 - "(10) LIFE-SUSTAINING TREATMENT. Any medical treatment, procedure, or intervention that, in the judgment of the attending physician, when applied to the patient, would serve only to prolong the dying process where the patient has a terminal illness or injury, or would serve only to maintain the patient in a condition of permanent unconsciousness. These procedures shall include, but are not limited to, assisted ventilation, cardiopulmonary resuscitation, renal dialysis, surgical procedures, blood transfusions, and the administration of drugs and antibiotics. Life-sustaining treatment shall not include the administration of medication or the performance of any medical treatment where, in the opinion of the attending physician, the medication or treatment is necessary to provide comfort or to alleviate pain.
 - "(11) LIVING WILL. A witnessed document in writing, voluntarily executed by the declarant, that gives directions

1	and may appoint a health care proxy, in accordance with the
2	requirements of Section 22-8A-4.
3	"(12) ORDER FOR PEDIATRIC PALLIATIVE AND END OF LIFE
4	(PPEL) CARE. A form signed by the attending physician of a
5	qualified minor in consultation with the representative of the
6	qualified minor, which when executed becomes the medical order
7	for all health care providers with respect to the extent of
8	use of emergency medical equipment and treatment, medication,
9	and any other technological or medical interventions available
10	to provide palliative and supportive care to the qualified
11	minor.
12	" $\frac{(12)}{(13)}$ PERMANENT UNCONSCIOUSNESS. A condition
13	that, to a reasonable degree of medical certainty:
14	"a. Will last permanently, without improvement; and
15	"b. In which cognitive thought, sensation,
16	purposeful action, social interaction, and awareness of self
17	and environment are absent; and
18	"c. Which condition has existed for a period of time
19	sufficient, in accordance with applicable professional
20	standards, to make such a diagnosis; and
21	"d. Which condition is confirmed by a physician who
22	is qualified and experienced in making such a diagnosis.
23	" $\frac{(13)}{(14)}$ PERSON. An individual, corporation,
24	business trust, estate, trust, partnership, association, joint
25	venture, government, governmental subdivision or agency, or
26	any other legal or commercial entity.

1	" $\frac{(14)}{(15)}$ PHYSICIAN. A person licensed to practice
2	medicine and osteopathy in the State of Alabama.
3	" (15) <u>(16)</u> PORTABLE PHYSICIAN DNAR ORDER. A DNAR
4	order entered in the medical record by a physician using the
5	required form designated by the State Board of Health and
6	substantiated by completion of all sections of the form.
7	"(17) QUALIFIED MINOR. An individual ranging in age
8	from birth until the age of 19 who has been diagnosed as a
9	terminally ill or injured patient and whose diagnosis has been
10	confirmed by at least one additional physician who is not the
11	patient's attending physician.
12	"(18) REPRESENTATIVE OF A QUALIFIED MINOR. Any of
13	the following with regard to a qualified minor:
14	"a. A parent of a qualified minor whose medical
15	decision making rights have not been restricted.
16	"b. A legal guardian of a qualified minor.
17	"c. A person acting as a parent, as the term is
18	defined in Section 30-3B-102.
19	" $\frac{(16)}{(19)}$ RESUSCITATIVE MEASURES. Those measures
20	used to restore or support cardiac or respiratory function in
21	the event of cardiopulmonary cessation.
22	" $\frac{(17)}{(20)}$ SURROGATE. Any person appointed to act or
23	behalf of an individual pursuant to Section 22-8A-11.
24	" (18) <u>(21)</u> TERMINALLY ILL OR INJURED PATIENT. A
25	patient whose death is imminent or whose condition, to a
26	reasonable degree of medical certainty, is hopeless unless he
27	or she is artificially supported through the use of

life-sustaining procedures and which condition is confirmed by a physician who is qualified and experienced in making such a diagnosis."

Section 3. Sections 22-8A-15 and 22-8A-16 are added to the Code of Alabama 1975, to read as follows:

\$22-8A-15.

- (a) A representative of a qualified minor shall have reasonable legal rights, duties, responsibilities, and obligations to act on behalf of the qualified minor. It is the intent of this section to recognize the desires of a qualified minor and of the representative of the qualified minor with respect to the extent of medical treatment, medication, and other interventions available to provide palliative and supportive care to the qualified minor. A representative of a qualified minor may request of the qualified minor's attending physician that an Order for Pediatric Palliative and End of Life (PPEL) Care be executed to carry out these desires.
- (b) The Department of Public Health, in consultation with the task force created pursuant to Section 22-8A-16, shall adopt rules not later than March 31, 2019, establishing the Order for PPEL Care form.
- (c) The desires of a representative of a qualified minor shall at all times supersede the effect of an Order for PPEL Care executed in accordance with this section.
- (d) Any health care provider or health care facility acting within the applicable standard of care who is attempting to follow the directives of an executed Order for

PPEL Care in compliance with this chapter is not subject to 1 2 criminal or civil liability and may not be found to have committed an act of unprofessional conduct. Nothing in this 3 chapter shall be construed to establish a standard of care for 4 5 physicians or otherwise modify, amend, or supersede any 6 provision of the Alabama Medical Liability Act of 1987, the 7 Alabama Medical Liability Act of 1996, or any amendment or judicial interpretation thereof. A health care provider or 8 9 health care facility who does not know, or could not 10 reasonably know, that an executed Order for PPEL Care exists is not civilly or criminally liable for actions taken to 11 assist a qualified minor subject to an executed Order for PPEL 12 13 Care.

\$22-8A-16.

14

15

16

17

18

19

20

21

22

23

24

25

- (a) A task force is created to serve under the supervision of the Alabama Department of Public Health, to establish the Order for PPEL Care form. The task force shall include all of the following representatives:
- (1) One representative of urban emergency medical services, appointed by the Governor.
- (2) One representative of rural emergency medical services, appointed by the Governor.
- (3) One pediatrician caring for medically complex children in an urban area, appointed by the Governor.
- (4) One pediatrician caring for medically complex children in a rural area, appointed by the Governor.

1	(5) Two pediatric specialists from any of the
2	following disciplines, appointed by the Governor: Oncology,
3	cardiology, neurology, or pulmonology.
4	(6) One pediatric ethicist, appointed by the
5	Governor.
6	(7) One nurse, appointed by the Alabama Board of
7	Nursing.
8	(8) The Director for School Nurses of the State
9	Department of Education, or his or her designee.
10	(9) The Director of Child Care Facilities of the
11	Department of Human Resources, or his or her designee.
12	(10) The State Health Officer, or his or her
13	designee.
14	(11) One pediatric certified registered nurse
15	practitioner, appointed by the Governor.
16	(12) Two social workers, appointed by the Governor.
17	(13) One representative of the Alabama Hospital
18	Association, appointed by the association.
19	(14) One representative of Children's Hospital of
20	Alabama, appointed by the hospital.
21	(15) One representative of Children's and Women's
22	Hospital at the University of South Alabama, appointed by the
23	hospital.
24	(16) One representative of the Alabama State
25	Advisory Council on Palliative Care and Quality of Life,

appointed by the organization.

- 1 (17) One representative of the Medical Association 2 of the State of Alabama, appointed by the association.
- (18) One representative of the Alabama Association 3 of School Nurses, appointed by the association. 4
- 5 (19) Two hospital chaplains, appointed by the 6 Governor.
- 7 (20) One pediatric palliative care physician, 8 appointed by the Governor.

11

12

13

16

17

18

19

20

21

22

23

24

- (21) One physician who practices hospital emergency 9 10 medicine, appointed by the Governor.
 - (22) One emergency medicine physician who practices at one of the Alabama licensed pediatric specialty hospitals, appointed by the Governor.
- (23) Two parents with minor children, appointed by 14 15 the President Pro Tempore of the Senate.
 - (24) Two parents with minor children, appointed by the Speaker of the House of Representatives.
 - (b) The appointing authorities shall coordinate their appointments to assure the task force membership is inclusive and reflects the racial, gender, geographic, urban, rural, and economic diversity of the state.
 - (c) The State Health Officer, or his or her designee, shall serve as chair of the task force.
- (d) The first meeting of the task force shall be held not later than June 1, 2018, at which time the task force may appoint or elect a vice chair. 26

1	(e) The task force shall automatically terminate on
2	the date the rules establishing the Order for PPEL Care form
3	are adopted.
4	Section 4. Section 22-8A-17 is added to the Code of
5	Alabama 1975, to read as follows:
6	\$22-8A-17.
7	An Order for Pediatric Palliative and End of Life
8	(PPEL) Care shall only apply in the school setting if the
9	order is included as part of a Palliative and End of Life
10	Individual Health Plan executed pursuant to Chapter 30B of
11	Title 16.
12	Section 5. Section 22-8A-17 is added to the Code of
13	Alabama 1975, to read as follows:
14	\$22-8A-17.
15	An Order for Pediatric Palliative and End of Life
16	Care shall not apply in the school setting.
17	Section 6. This act shall become effective
18	immediately following its passage and approval by the
19	Governor, or its otherwise becoming law, except Section 4 only
20	becomes effective upon the passage of HB202 of the 2018
21	Regular Session, relating to Palliative and End of Life
22	Individual Health Plans, and Section 5 only becomes effective
23	if HB202 of the 2018 Regular Session is not enacted into law.

Τ	
2	
3	House of Representatives
4 5 6 7	Read for the first time and re- ferred to the House of Representa- tives committee on Health 11-JAN-18
8 9 10	Read for the second time and placed on the calendar 1 amendment 25-JAN-18
11 12 13	Read for the third time and passed as amended
14 15 16	Jeff Woodard Clerk