- 1 HB194
- 2 188155-5
- 3 By Representative Weaver
- 4 RFD: Health
- 5 First Read: 11-JAN-18

1	188155-5:n	:01/11/2018:PMG*/th LSA2017-2958R4
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8	SYNOPSIS:	Under existing law, an adult or a health
9		care proxy for an adult may execute an advance
10		directive for health care or do not resuscitate
11		order.
12		This bill would create the Alex Hoover Act.
13		This bill would require the Department of
14		Public Health, by rule and in conjunction with a
15		task force, to establish a form for an Order for
16		Pediatric Palliative and End of Life (PPEL) Care to
17		be used by medical professionals outlining medical
18		care provided to a minor with a terminal illness.
19		This bill would provide immunity to health
20		care providers who provide, withhold, or withdraw
21		medical treatment pursuant to an Order for PPEL
22		Care.
23		This bill would also establish a temporary
24		task force to work in consultation with the
25		Department of Public Health to establish an Order
26		for Pediatric Palliative and End of Life (PPEL)
27		Care form.

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2	A BILL
3	TO BE ENTITLED
4	AN ACT
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6	Relating to terminally ill minors; to amend Sections
7	22-8A-2, 22-8A-3, and 22-8A-7, Code of Alabama 1975; to add
8	Sections 22-8A-15 to 22-8A-18, inclusive, to the Code of
9	Alabama 1975; to create the Alex Hoover Act; to require the
10	Department of Public Health, by rule and in conjunction with a
11	task force, to establish a form for an Order for Pediatric
12	Palliative and End of Life (PPEL) Care to be used by medical
13	professionals outlining medical care provided to terminally
14	ill minors in certain circumstances; to provide immunity to
15	health care providers who provide, withhold, or withdraw
16	medical treatment pursuant to an Order for PPEL Care; and to
17	establish a temporary task force to work in consultation with
18	the Department of Public Health to establish an Order for
19	Pediatric Palliative and End of Life (PPEL) Care form.
20	BE IT ENACTED BY THE LEGISLATURE OF ALABAMA:
21	Section 1. This act shall be known and may be cited
22	as the Alex Hoover Act.
23	Section 2. Sections 22-8A-2, 22-8A-3, and 22-8A-7,
24	Code of Alabama 1975, are amended to read as follows:
25	"§22-8A-2.
26	"(a) The Legislature finds that competent adult
27	persons and qualified representatives of qualified minors 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.

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"(b) 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 or a qualified representative of a qualified minor 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 or qualified minor 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 and to allow a health care provider to follow certain portable physician orders for adults and qualified 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:

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- "(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 assisted feeding, such as spoon or bottle feeding.
 - "(3) ADVANCE DIRECTIVE FOR HEALTH CARE. A writing executed in accordance with Section 22-8A-4 which may include a living will, the appointment of a health care proxy, or both such living will and appointment of a health care proxy.
 - "(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, 1 2 physician orders written as "do not resuscitate," "do not allow resuscitation, " "do not allow resuscitative measures, " 3 "DNAR," "DNR," "allow natural death," or "AND." A do not 5 attempt resuscitation order must be entered with the consent 6 of the person, if the person is competent; or in accordance 7 with instructions in an advance directive if the person is not 8 competent or is no longer able to understand, appreciate, and 9 direct his or her medical treatment and has no hope of 10 regaining that ability; or with the consent of a health care proxy or surrogate functioning under the provisions in this 11 12 chapter; or instructions by an attorney in fact under a 13 durable power of attorney that duly grants powers to the attorney in fact to make those decisions described in Section 14 15 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.

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- "(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 and may appoint a health care proxy, in accordance with the requirements of Section 22-8A-4.

"(12) ORDER FOR PEDIATRIC PALLIATIVE AND END OF LIFE

(PPEL) CARE. A form signed by the attending physician of a

qualified minor in consultation with the qualified

representative of a qualified minor, which when completed

becomes the medical order for all health care providers with

respect to the extent of use of emergency medical equipment

and treatment, medication, and any other technological or

medical interventions available to provide palliative and

supportive care to the qualified minor.

" $\frac{(12)}{(13)}$ PERMANENT UNCONSCIOUSNESS. A condition that, to a reasonable degree of medical certainty:

"a. Will last permanently, without improvement; and

Τ	"b. In which cognitive thought, sensation,
2	purposeful action, social interaction, and awareness of self
3	and environment are absent; and
4	"c. Which condition has existed for a period of time
5	sufficient, in accordance with applicable professional
6	standards, to make such a diagnosis; and
7	"d. Which condition is confirmed by a physician who
8	is qualified and experienced in making such a diagnosis.
9	" $\frac{(13)}{(14)}$ PERSON. An individual, corporation,
10	business trust, estate, trust, partnership, association, joint
11	venture, government, governmental subdivision or agency, or
12	any other legal or commercial entity.
13	" $\frac{(14)}{(15)}$ PHYSICIAN. A person licensed to practice
14	medicine and osteopathy in the State of Alabama.
15	" $\frac{(15)}{(16)}$ PORTABLE PHYSICIAN DNAR ORDER. A DNAR
16	order entered in the medical record by a physician using the
17	required form designated by the State Board of Health and
18	substantiated by completion of all sections of the form.
19	"(17) QUALIFIED MINOR. An individual ranging in age
20	from birth until the age of 19 who has been diagnosed as
21	terminally ill or injured. For purposes of this chapter, a
22	qualified minor shall be considered an adult when acting
23	through a qualified representative under this chapter only as
24	permitted and set forth in this chapter.
25	"(18) QUALIFIED REPRESENTATIVE. Any of the following
26	with regard to a qualified minor:

1	"a. A parent of a qualified minor whose medical
2	decision making rights have not been restricted.
3	"b. A legal guardian of a qualified minor, which may
4	include situations where the Department of Human Resources has
5	<pre>custody of a minor.</pre>
6	"c. An adult acting in loco parentis on behalf of a
7	qualified minor.
8	" $\frac{(16)}{(19)}$ RESUSCITATIVE MEASURES. Those measures
9	used to restore or support cardiac or respiratory function in
10	the event of cardiopulmonary cessation.
11	" $\frac{(17)}{(20)}$ SURROGATE. Any person appointed to act on
12	behalf of an individual pursuant to Section 22-8A-11.
13	" (18) <u>(21)</u> TERMINALLY ILL OR INJURED PATIENT. A
14	patient whose death is imminent or whose condition, to a
15	reasonable degree of medical certainty, is hopeless unless he
16	or she is artificially supported through the use of
17	life-sustaining procedures and which condition is confirmed by
18	a physician who is qualified and experienced in making such a
19	diagnosis.
20	"§22-8A-7.
21	"(a) A competent adult or a qualified representative
22	of a qualified minor may make decisions regarding
23	life-sustaining treatment and artificially provided nutrition
24	and hydration so long as that individual is able to do so. The
25	desires of an individual or qualified representative shall at
26	all times supersede the effect of an advance directive for

health care or an Order for Pediatric Palliative and End of

Life Care.

"(b) If the individual is not competent at the time of the decision to provide, withhold, or withdraw life-sustaining treatment or artificially provided nutrition and hydration, an Order for Pediatric Palliative and End of Life Care, a living will executed in accordance with Section 22-8A-4(a), or a proxy designation executed in accordance with Section 22-8A-4(b) is presumed to be valid. For the purpose of this chapter, a health care provider may presume in the absence of actual notice to the contrary that an individual who executed an advance directive for health care was competent when it was executed. The fact of an individual's having executed an advance directive for health care shall not be considered as an indication of a declarant's mental incompetency. Advanced age of itself shall not be a bar to a determination of competency.

"(c) No physician, licensed health care professional, medical care facility, other health care provider, or any employee thereof who in good faith and pursuant to reasonable medical standards issues or follows an Order for Pediatric Palliative and End of Life Care or a portable physician DNAR order entered in the medical record pursuant to this chapter, or causes or participates in the providing, withholding, or withdrawing of life-sustaining treatment or artificially provided nutrition and hydration from a patient pursuant to an Order for Pediatric Palliative

1 and End of Life Care, a living will, or designated proxy made 2 in accordance with this chapter or pursuant to the directions of a duly designated surrogate appointed in accordance with 3 this chapter, in the absence of actual knowledge of the 4 5 revocation thereof, shall, as a result thereof, be subject to criminal or civil liability, or be found to have committed an 6 7 act of unprofessional conduct." Section 3. Sections 22-8A-15 to 22-8A-17, inclusive, 9 are added to the Code of Alabama 1975, to read as follows: 10 \$22-8A-15. (a) For purposes of this chapter, a qualified 11 12 representative may act on behalf of a qualified minor in the 13 following circumstances: (1) Executing an advance directive for health care 14 15 under Section 22-8A-4. (2) Consenting to a DNAR order under Section 16 22-8A-4.1. 17 18 (3) Revoking an advanced directive for health care pursuant to Section 22-8A-5. 19 2.0 (4) Acting as a designated proxy under Section 21 22-8A-6. (5) Acting as a surrogate under Section 22-8A-11. 22 23 (b) A qualified representative shall have reasonable 24 legal rights, duties, responsibilities, and obligations to act 25 on behalf of a qualified minor.

\$22-8A-16.

- 1 (a) The Department of Public Health, in consultation
 2 with the task force created pursuant to Section 22-8A-17,
 3 shall adopt rules not later than March 31, 2019, establishing
 4 the Order for Pediatric Palliative and End of Life (PPEL) Care
 5 form.
 - (b) No physician, licensed health care professional, medical care facility, other health care provider, or any employee thereof who in good faith and pursuant to reasonable medical practice issues or follows an Order for Pediatric Palliative and End of Life (PPEL) Care entered in the medical record pursuant to this chapter, or causes or participates in the providing, withholding, or withdrawing of life-sustaining treatment or artificially provided nutrition and hydration from a patient pursuant to the Order for PPEL Care, in the absence of actual knowledge of the revocation thereof, shall, as a result thereof, be subject to criminal or civil liability, or be found to have committed an act of unprofessional conduct.

\$22-8A-17.

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

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- 1 (16) One representative of the Alabama State 2 Advisory Council on Palliative Care and Quality of Life, 3 appointed by the organization. (17) One representative of the Medical Association 4 5 of the State of Alabama, appointed by the association. 6 (18) One representative of the Alabama Association 7 of School Nurses, appointed by the association. (19) Two hospital chaplains, appointed by the 8 9 Governor. 10 (20) One pediatric palliative care physician, 11 appointed by the Governor. (21) One physician who practices hospital emergency 12 13 medicine, appointed by the Governor. (22) One emergency medicine physician who practices 14 15 at one of the Alabama licensed pediatric specialty hospitals, 16 appointed by the Governor. 17 (23) Two parents with minor children, appointed by the President Pro Tempore of the Senate. 18 (24) Two parents with minor children, appointed by 19 2.0 the Speaker of the House of Representatives. 21 (b) The appointing authorities shall coordinate 22 their appointments to assure the task force membership is inclusive and reflects the racial, gender, geographic, urban, 23
 - (c) The State Health Officer, or his or her designee, shall serve as chair of the task force.

rural, and economic diversity of the state.

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- 1 (d) The first meeting of the task force shall be
 2 held not later than June 1, 2018, at which time the task force
 3 may appoint or elect a vice chair.
- 4 (e) The task force shall automatically terminate on
 5 the date the rules establishing the Order for PPEL Care form
 6 are adopted.

Section 4. Section 22-8A-18 is added to the Code of Alabama 1975, to read as follows:

9 §22-8A-18.

An Order for Pediatric Palliative and End of Life (PPEL) Care shall only apply in the school setting if the order is included as part of a Palliative and End of Life Individual Health Plan executed pursuant to Chapter 30B of Title 16.

Section 5. Section 22-8A-18 is added to the Code of Alabama 1975, to read as follows:

17 \$22-8A-18.

An Order for Pediatric Palliative and End of Life Care shall not apply in the school setting.

Section 6. This act shall become effective immediately following its passage and approval by the Governor, or its otherwise becoming law, except Section 4 only becomes effective upon the passage of HB202 of the 2018 Regular Session, relating to Palliative and End of Life Individual Health Plans, and Section 5 only becomes effective if HB202 of the 2018 Regular Session is not enacted into law.