- 1 НВЗ73
- 2 186144-3
- 3 By Representatives Weaver and McCutcheon
- 4 RFD: Health
- 5 First Read: 07-MAR-17

1	ENGROSSED
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3	
4	A BILL
5	TO BE ENTITLED
6	AN ACT
7	
8	Relating to terminally ill minors; to amend Sections
9	22-8A-2, 22-8A-3, and 22-8A-7, as last amended by Act 2016-96,
10	2016 Regular Session, Code of Alabama 1975; to add Sections
11	22-8A-15 to 22-8A-18, inclusive, to the Code of Alabama 1975;
12	to create the Alex Hoover Act; to provide for palliative and
13	end of life individual health plans to be created by the
14	parents or guardians of a minor with a terminal illness; to
15	provide civil and criminal immunity to individuals, health
16	care providers, and schools, who undertake to follow the
17	directives of a palliative and end of life individual health
18	plan; to establish a task force to work in conjunction with
19	the Department of Public Health to establish a Physician Order
20	for Pediatric Palliative and End of Life (PPEL) Care form; to
21	require the State Board of Education to promulgate rules
22	establishing a palliative and end of life individual health
23	plan form and its contents to be used in a school setting; and
24	to require the Department of Public Health to promulgate rules
25	for palliative and end of life individual health plans used
26	outside of the school setting.
27	BE IT ENACTED BY THE LEGISLATURE OF ALABAMA:

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

3 Section 2. Sections 22-8A-2, 22-8A-3, and 22-8A-7,
4 as last amended by Act 2016-96, 2016 Regular Session, Code of
5 Alabama 1975, are amended to read as follows:

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"§22-8A-2.

7 "(a) The Legislature finds that competent adult persons and qualified representatives of qualified minors have 8 the right to control the decisions relating to the rendering 9 10 of their own medical care, including, without limitation, the 11 decision to have medical procedures, life-sustaining 12 treatment, and artificially provided nutrition and hydration 13 provided, withheld, or withdrawn in instances of terminal 14 conditions and permanent unconsciousness.

15 "(b) In order that the rights of individuals may be 16 respected even after they are no longer able to participate 17 actively in decisions about themselves, the Legislature 18 hereby declares that the laws of this state shall recognize 19 the right of a competent adult person and a qualified 20 representative of a qualified minor to make a written 21 declaration instructing his or her a physician to provide, 22 withhold, or withdraw life-sustaining treatment and 23 artificially provided nutrition and hydration or designate by 24 lawful written form a health care proxy to make decisions on 25 behalf of the adult person, or qualified representative of a 26 qualified minor, concerning the providing, withholding, or 27 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 <u>for adults and</u> <u>qualified minors as</u> provided for in this chapter.

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"§22-8A-3.

9 "As used in this chapter, the following terms shall 10 have the following meanings, respectively, unless the context 11 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.

19 "(3) ADVANCE DIRECTIVE FOR HEALTH CARE. A writing 20 executed in accordance with Section 22-8A-4 which may include 21 a living will, the appointment of a health care proxy, or both 22 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.

26 "(5) CARDIOPULMONARY CESSATION. A lack of pulse or27 respiration.

1 "(6) COMPETENT ADULT. An adult who is alert, capable 2 of understanding a lay description of medical procedures and 3 able to appreciate the consequences of providing, withholding, 4 or withdrawing medical procedures.

5 "(7) DO NOT ATTEMPT RESUSCITATION (DNAR) ORDER. A physician's order that resuscitative measures not be provided 6 7 to a person under a physician's care in the event the person 8 is found with cardiopulmonary cessation. A do not attempt resuscitation order would include, without limitation, 9 10 physician orders written as "do not resuscitate," "do not allow resuscitation," "do not allow resuscitative measures," 11 12 "DNAR," "DNR," "allow natural death," or "AND." A do not 13 attempt resuscitation order must be entered with the consent 14 of the person, if the person is competent; or in accordance 15 with instructions in an advance directive if the person is not 16 competent or is no longer able to understand, appreciate, and 17 direct his or her medical treatment and has no hope of 18 regaining that ability; or with the consent of a health care 19 proxy or surrogate functioning under the provisions in this 20 chapter; or instructions by an attorney in fact under a 21 durable power of attorney that duly grants powers to the 22 attorney in fact to make those decisions described in Section 23 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.

3 "(9) HEALTH CARE PROXY. Any person designated to act
4 on behalf of an individual pursuant to Section 22-8A-4.

5 "(10) LIFE-SUSTAINING TREATMENT. Any medical treatment, procedure, or intervention that, in the judgment of 6 7 the attending physician, when applied to the patient, would serve only to prolong the dying process where the patient has 8 a terminal illness or injury, or would serve only to maintain 9 10 the patient in a condition of permanent unconsciousness. These 11 procedures shall include, but are not limited to, assisted 12 ventilation, cardiopulmonary resuscitation, renal dialysis, 13 surgical procedures, blood transfusions, and the administration of drugs and antibiotics. Life-sustaining 14 treatment shall not include the administration of medication 15 16 or the performance of any medical treatment where, in the opinion of the attending physician, the medication or 17 treatment is necessary to provide comfort or to alleviate 18 19 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.

24 "(12) PALLIATIVE AND END OF LIFE INDIVIDUAL HEALTH
 25 PLAN. A document that outlines health care to be provided to a
 26 qualified minor, in a school setting, developed by a school
 27 nurse in conjunction with the qualified representative,

pursuant to Section 22-8A-16. A palliative and end of life 1 2 individual health plan shall include a copy of the physician 3 order for PPEL care and may contain any other directive or 4 order executed pursuant to this chapter on behalf of the qualified minor. 5 "(12) (13) PERMANENT UNCONSCIOUSNESS. A condition 6 7 that, to a reasonable degree of medical certainty: 8 "a. Will last permanently, without improvement; and "b. In which cognitive thought, sensation, 9 10 purposeful action, social interaction, and awareness of self 11 and environment are absent; and 12 "c. Which condition has existed for a period of time 13 sufficient, in accordance with applicable professional standards, to make such a diagnosis; and 14 15 "d. Which condition is confirmed by a physician who 16 is qualified and experienced in making such a diagnosis. 17 "(13) (14) PERSON. An individual, corporation, 18 business trust, estate, trust, partnership, association, joint 19 venture, government, governmental subdivision or agency, or 20 any other legal or commercial entity. "(14) (15) PHYSICIAN. A person licensed to practice 21 22 medicine and osteopathy in the State of Alabama. 23 "(16) PHYSICIAN ORDER FOR PEDIATRIC PALLIATIVE AND END OF LIFE (PPEL) CARE. A form signed by the treating 24 25 physician of a qualified minor using the form developed by the 26 Department of Public Health, in conjunction with the 27 Governor's task force pursuant to Section 4 of the act

1	amending this section, signed by the physician directing the
2	care of the qualified minor, which when completed becomes the
3	order directing all professional caregivers with respect to
4	the extent of use of emergency medical equipment, medication,
5	and any other technological interventions available to provide
6	palliative and supportive care to the qualified minor.
7	" (15) <u>(17)</u> portable physician dnar order. A dnar
8	order entered in the medical record by a physician using the
9	required form designated by the State Board of Health and
10	substantiated by completion of all sections of the form.
11	" <u>(18) QUALIFIED MINOR. An individual ranging in age</u>
12	from birth until the age of 19 who has been diagnosed as
13	terminally ill or injured. For purposes of this chapter, a
14	qualified minor shall be considered an adult when acting
15	through a qualified representative under this chapter only as
16	permitted and set forth in this chapter.
17	"(19) QUALIFIED REPRESENTATIVE. Any of the following
18	with regard to a qualified minor:
19	"a. A parent of a qualified minor whose medical
20	decision making rights have not been restricted.
21	"b. A legal guardian of a qualified minor, which may
22	include situations where the Department of Human Resources has
23	custody of a minor.
24	" <u>c. An adult acting in loco parentis on behalf of a</u>
25	qualified minor.

"(16) (20) RESUSCITATIVE MEASURES. Those measures
 used to restore or support cardiac or respiratory function in
 the event of cardiopulmonary cessation.

4 "(17) (21) SURROGATE. Any person appointed to act on
5 behalf of an individual pursuant to Section 22-8A-11.

6 "(18) (22) TERMINALLY ILL OR INJURED PATIENT. A 7 patient whose death is imminent or whose condition, to a 8 reasonable degree of medical certainty, is hopeless unless he 9 or she is artificially supported through the use of 10 life-sustaining procedures and which condition is confirmed by 11 a physician who is qualified and experienced in making such a 12 diagnosis.

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"§22-8A-7.

14 "(a) A competent adult may make decisions regarding 15 life-sustaining treatment and artificially provided nutrition 16 and hydration so long as that individual is able to do so. The 17 desires of an individual shall at all times supersede the 18 effect of an advance directive for health care.

19 "(b) If the individual is not competent at the time 20 of the decision to provide, withhold, or withdraw 21 life-sustaining treatment or artificially provided nutrition 22 and hydration, a living will executed in accordance with 23 Section 22-8A-4(a) or a proxy designation executed in 24 accordance with Section 22-8A-4(b) is presumed to be valid. 25 For the purpose of this chapter, a health care provider may 26 presume in the absence of actual notice to the contrary that 27 an individual who executed an advance directive for health

1 care was competent when it was executed. The fact of an
2 individual's having executed an advance directive for health
3 care shall not be considered as an indication of a declarant's
4 mental incompetency. Advanced age of itself shall not be a bar
5 to a determination of competency.

"(c) No physician, licensed health care 6 7 professional, medical care facility, other health care provider, or any employee thereof who in good faith and 8 pursuant to reasonable medical standards issues or follows a 9 10 portable physician DNAR order or a Physician Order for PPEL 11 Care entered in the medical record pursuant to this chapter or 12 causes or participates in the providing, withholding, or 13 withdrawing of life-sustaining treatment or artificially provided nutrition and hydration from a patient pursuant to a 14 15 living will or designated proxy made in accordance with this 16 chapter or pursuant to the directions of a duly designated 17 surrogate appointed in accordance with this chapter, in the 18 absence of actual knowledge of the revocation thereof, shall, 19 as a result thereof, be subject to criminal or civil 20 liability, or be found to have committed an act of unprofessional conduct." 21

22 Section 3. Sections 22-8A-15, 22-8A-16, 22-8A-17, 23 and 22-8A-18 are added to the Code of Alabama 1975, to read as 24 follows:

25 §22-8A-15.

(a) For purposes of this chapter, a qualified 1 2 representative may act on behalf of a qualified minor in the 3 following circumstances: (1) Executing an advance directive for health care 4 under Section 22-8A-4. 5 (2) Consenting to a DNAR order under Section 6 7 22-8A-4.1. (3) Revoking an advanced directive for health care 8 pursuant to Section 22-8A-5. 9 10 (4) Executing a palliative and end of life 11 individual health plan pursuant to Section 22-8A-16. 12 (5) Acting as a designated proxy under Section 13 22-8A-6. (6) Acting as a surrogate under Section 22-8A-11. 14 15 (b) A qualified representative shall have legal 16 rights, duties, responsibilities, and obligations to act in a 17 fiduciary capacity on behalf of a qualified minor. 18 §22-8A-16. 19 (a) As used in this section and Section 22-8A-17, 20 school means any K-12 public school, charter school, any educational or correctional institution under the control of 21 22 the Department of Youth Services, the Alabama Institute for 23 Deaf and Blind, the Alabama School of Fine Arts, and the 24 Alabama School of Math and Science. 25 (b) As a prerequisite to executing any directives, 26 orders, or guidance on behalf of a qualified minor regarding

care and services in a school, a qualified representative

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1 shall complete a palliative and end of life individual health 2 plan and file a copy of the plan with any school the qualified 3 minor attends.

4 (c) The form and contents of the palliative and end 5 of life individual health plan shall be developed pursuant to 6 rules promulgated by the State Board of Education, in 7 consultation with the Department of Public Health and the 8 Alabama Board of Nursing, with special consideration given to 9 meet child and family needs, as well as the needs of students 10 and staff.

(d) The palliative and end of life individual health plan shall include a copy of the Physician Order for PPEL Care and any of the following:

14 (1) A copy of any other directive or order executed15 pursuant to this chapter on behalf of the qualified minor.

16 (2) A detailed listing of expectations of
17 non-medical care as it applies to non-medical professionals
18 and other individuals specifically addressing circumstances in
19 anticipation of the death of the qualified minor.

(3) A detailed plan of action for the school in the
event of a qualified minor's death while participating in a
school activity, including guidance and plans for addressing
the needs of other children who may witness the death of the
minor.

(4) A detailed plan of action for the school in the
event of a qualified minor's death while on school property or

1 at a school event, with regard to what should be done with the 2 body of the qualified minor.

3 (5) The specific types of school-sanctioned
4 activities authorized by the qualified representative in which
5 the qualified minor may participate.

(6) A narrative description of the desire for 6 7 participating in activities or organizations within the community, including school-sanctioned activities at school 8 during school hours and after school hours, in which the 9 10 qualified minor may participate. The written desire for 11 participating in school-sanctioned activities does not 12 constitute a guarantee of participation. The qualified minor 13 shall meet the same participation requirements for school-sanctioned activities as set forth for all students at 14 the school. 15

16 (7) An acknowledgement by the gualified 17 representative that physicians, nurses, health care providers, 18 health care facilities, schools, school boards, school board 19 members, and employees of a local board of education, and 20 other individuals acting in consultation with the school are 21 not criminally or civilly liable for following any plans, 22 guidance, or directives of the palliative and end of life 23 individual health plan.

(8) An acknowledgement by the qualified
representative that he or she has been provided information
about the risks and benefits of the activities as described in

the palliative and end of life individual health plan and how the activities may affect the death of the qualified minor.

3 (9) Any other requirement that may be established by4 rule in accordance with this chapter.

5 (e) A palliative and end of life individual health 6 plan is executed when it is completed and signed and dated by 7 all qualified representatives of the qualified minor.

8 (f) After a palliative and end of life individual 9 health plan is executed, the school, upon written consent by 10 the qualified representatives, shall notify, to the extent 11 possible, local emergency medical services of the presence of 12 a qualified minor in the school with a palliative and end of 13 life individual health plan.

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§22-8A-17.

Any individual, physician, nurse, health care 15 provider, health care facility, school, city or county board 16 17 of education, the Board of Education for the Department of 18 Youth Services, board of education member, or employee of a 19 local board of education or school, attempting to follow a 20 palliative and end of life individual health plan or 21 directions, guidance, or instructions provided by a qualified 22 representative pursuant to a palliative and end of life 23 individual health plan shall not be subject to criminal or 24 civil liability. When interpreting this chapter, all defenses 25 and immunities herein shall inure to the benefit of those 26 individuals, physicians, nurses, health care providers, health 27 care facilities, schools, local boards of education, board of

education members, and employees of a local board of education 1 or school. Furthermore, no individual shall be subject to 2 criminal or civil liability for the provision of medical or 3 4 non-medical care or treatment or withholding of treatment of a 5 qualified minor as provided for under this chapter. This protection extends to these individuals regardless of whether 6 7 or not the condition that causes the death is, in fact, the cause of the qualified minor's death. 8

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§22-8A-18.

(a) The State Board of Education, in consultation
with the Department of Public Health and the Alabama Board of
Nursing, shall promulgate any rules necessary to carry out
Section 22-8A-16 within a school setting for the care of a
qualified minor.

(b) The Department of Public Health, in consultation with the State Department of Education and the Alabama Board of Nursing, shall promulgate any rules necessary to carry out Section 22-8A-16 outside of a school for the care of a gualified minor.

20 Section 4. (a) The Department of Public Health, in 21 conjunction with the task force created pursuant to subsection 22 (b), shall promulgate rules establishing the Physician Order 23 for Pediatric Palliative and End of Life (PPEL) Care form.

(b) The Governor shall appoint a task force, to
serve for no more than two years under the supervision of the
Alabama Department of Public Health, to establish the

2 include all of the following representatives: (1) A representative of urban emergency medical 3 4 services, appointed by the Governor. 5 (2) A representative of rural emergency medical services, appointed by the Governor. 6 7 (3) A pediatrician caring for medically complex 8 children in an urban area, appointed by the Governor. (4) A pediatrician caring for medically complex 9 10 children in a rural area, appointed by the Governor. 11 (5) Two pediatric specialists from any of the 12 following disciplines, appointed by the Governor: Oncology, 13 cardiology, neurology, or pulmonology. (6) A pediatric ethicist, appointed by the Governor. 14 15 (7) A nurse, appointed by the Alabama Board of 16 Nursing. 17 (8) The Director for School Nurses of the State 18 Department of Education, or his or her designee. 19 (9) The Director Child Care Facilities of the 20 Department of Human Resources, or his or her designee. (10) The State Health Officer, or his or her 21 22 designee. 23 (11) A pediatric advanced practice practitioner, 24 appointed by the Governor. 25 (12) Two social workers, appointed by the Governor. 26 (13) A representative of the Alabama Hospital 27 Association appointed by the association.

Physician Order for PPEL Care form. The task force shall

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(14) A representative of Children's Hospital of
 Alabama appointed by the hospital.

3 (15) A representative of Children's and Women's
4 Hospital at the University of South Alabama appointed by the
5 hospital.

6 (16) A representative of the Alabama State Advisory
7 Council on Palliative Care and Quality of Life appointed by
8 the organization.

9 (17) A representative of the Medical Association of
10 Alabama, appointed by the association.

(18) A representative of the Alabama Association of
School Nurses, appointed by the association.

13 (19) Two hospital chaplains appointed by the14 Governor.

15 (20) A pediatric palliative care physician,16 appointed by the Governor.

17 (21) A physician who practices hospital emergency18 medicine, appointed by the Governor.

19 (22) An emergency medicine physician who practices
20 at one of the Alabama licensed pediatric specialty hospitals
21 appointed by the Governor.

(23) Two parents with minor children, appointed bythe President Pro Tempore of the Senate.

24 (24) Two parents with minor children, appointed by
25 the Speaker of the House of Representatives.

1	(c) The task force shall provide an annual report to
2	the Legislature no later than the 15th legislative day of the
3	regular session.
4	Section 5. The appointing authorities shall
5	coordinate their appointments to assure the task force
6	membership is inclusive and reflects the racial, gender,
7	geographic, urban, rural, and economic diversity of the state.
8	Section 6. This act shall become effective three
9	months following its passage and approval by the Governor, or
10	its otherwise becoming law.

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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
8 9 10 11	Read for the second time and placed on the calendar with 1 substitute and 15-MAR-17
12 13	Read for the third time and passed as amended
14	Yeas 98, Nays 0, Abstains 0

15 16 17 18

Jeff Woodard Clerk