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3 SUBSTITUTE FOR HB373  
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8 SYNOPSIS: Under existing law, an adult or health care  
9 proxy may execute an advance directive for health  
10 care or do not resuscitate order.

11 This bill would create the Alex Hoover Act.

12 This bill would provide for palliative and  
13 end of life individual health plans to be created  
14 by the parents or guardians of a minor with a  
15 terminal illness.

16 This bill would provide civil and criminal  
17 immunity to individuals, health care providers, and  
18 schools, who undertake to follow the directives of  
19 a palliative and end of life individual health  
20 plan.

21 This bill would establish a task force to  
22 work in conjunction with the Department of Public  
23 Health to establish a Physician Order for Pediatric  
24 Palliative and End of Life (PPEL) Care form.

25 This bill would require the State Board of  
26 Education, in consultation with the Department of  
27 Public Health and the Alabama Board of Nursing to

1 promulgate rules establishing a palliative and end  
2 of life individual health plan form and its  
3 contents to be used in a school setting.

4 This bill would also require the Department  
5 of Public Health, in consultation with the State  
6 Department of Education and the Alabama Board of  
7 Nursing, to promulgate rules for palliative and end  
8 of life individual health plans used outside of the  
9 school setting.

10  
11 A BILL  
12 TO BE ENTITLED  
13 AN ACT  
14

15 Relating to terminally ill minors; to amend Sections  
16 22-8A-2, 22-8A-3, and 22-8A-7, as last amended by Act 2016-96,  
17 2016 Regular Session, Code of Alabama 1975; to add Sections  
18 22-8A-15 to 22-8A-18, inclusive, to the Code of Alabama 1975;  
19 to create the Alex Hoover Act; to provide for palliative and  
20 end of life individual health plans to be created by the  
21 parents or guardians of a minor with a terminal illness; to  
22 provide civil and criminal immunity to individuals, health  
23 care providers, and schools, who undertake to follow the  
24 directives of a palliative and end of life individual health  
25 plan; to establish a task force to work in conjunction with  
26 the Department of Public Health to establish a Physician Order  
27 for Pediatric Palliative and End of Life (PPEL) Care form; to

1 require the State Board of Education to promulgate rules  
2 establishing a palliative and end of life individual health  
3 plan form and its contents to be used in a school setting; and  
4 to require the Department of Public Health to promulgate rules  
5 for palliative and end of life individual health plans used  
6 outside of the school setting.

7 BE IT ENACTED BY THE LEGISLATURE OF ALABAMA:

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

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

13 "§22-8A-2.

14 "(a) The Legislature finds that competent adult  
15 persons and qualified representatives of qualified minors have  
16 the right to control the decisions relating to the rendering  
17 of ~~their own~~ medical care, including, without limitation, the  
18 decision to have medical procedures, life-sustaining  
19 treatment, and artificially provided nutrition and hydration  
20 provided, withheld, or withdrawn in instances of terminal  
21 conditions and permanent unconsciousness.

22 "(b) In order that the rights of individuals may be  
23 respected even after they are no longer able to participate  
24 actively in decisions about themselves, the Legislature  
25 hereby declares that the laws of this state shall recognize  
26 the right of a competent adult person and a qualified  
27 representative of a qualified minor to make a written

1 declaration instructing ~~his or her~~ a physician to provide,  
2 withhold, or withdraw life-sustaining treatment and  
3 artificially provided nutrition and hydration or designate by  
4 lawful written form a health care proxy to make decisions on  
5 behalf of the adult person, or qualified representative of a  
6 qualified minor, concerning the providing, withholding, or  
7 withdrawing of life-sustaining treatment and artificially  
8 provided nutrition and hydration in instances of terminal  
9 conditions and permanent unconsciousness. The Legislature  
10 further desires to provide for the appointment of surrogate  
11 decision-makers in instances where the individual has not made  
12 such a designation and to allow a health care provider to  
13 follow certain portable physician orders for adults and  
14 qualified minors as provided for in this chapter.

15 "§22-8A-3.

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

19 "(1) ADULT. Any person 19 years of age or over.

20 "(2) ARTIFICIALLY PROVIDED NUTRITION AND HYDRATION.

21 A medical treatment consisting of the administration of food  
22 and water through a tube or intravenous line, where the  
23 recipient is not required to chew or swallow voluntarily.  
24 Artificially provided nutrition and hydration does not include  
25 assisted feeding, such as spoon or bottle feeding.

26 "(3) ADVANCE DIRECTIVE FOR HEALTH CARE. A writing  
27 executed in accordance with Section 22-8A-4 which may include

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

3 "(4) ATTENDING PHYSICIAN. The physician selected by,  
4 or assigned to, the patient who has primary responsibility for  
5 the treatment and care of the patient.

6 "(5) CARDIOPULMONARY CESSATION. A lack of pulse or  
7 respiration.

8 "(6) COMPETENT ADULT. An adult who is alert, capable  
9 of understanding a lay description of medical procedures and  
10 able to appreciate the consequences of providing, withholding,  
11 or withdrawing medical procedures.

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

1 durable power of attorney that duly grants powers to the  
2 attorney in fact to make those decisions described in Section  
3 22-8A-4(b) (1) .

4 "(8) HEALTH CARE PROVIDER. A person who is licensed,  
5 certified, registered, or otherwise authorized by the law of  
6 this state to administer or provide health care in the  
7 ordinary course of business or in the practice of a  
8 profession.

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

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

26 "(11) LIVING WILL. A witnessed document in writing,  
27 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) PALLIATIVE AND END OF LIFE INDIVIDUAL HEALTH  
4 PLAN. A document that outlines health care to be provided to a  
5 qualified minor, in a school setting, developed by a school  
6 nurse in conjunction with the qualified representative,  
7 pursuant to Section 22-8A-16. A palliative and end of life  
8 individual health plan shall include a copy of the physician  
9 order for PPEL care and may contain any other directive or  
10 order executed pursuant to this chapter on behalf of the  
11 qualified minor.

12 ~~"(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 ~~"(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           "~~(14)~~ (15) PHYSICIAN. A person licensed to practice  
2 medicine and osteopathy in the State of Alabama.

3           "(16) PHYSICIAN ORDER FOR PEDIATRIC PALLIATIVE AND  
4 END OF LIFE (PPEL) CARE. A form signed by the treating  
5 physician of a qualified minor using the form developed by the  
6 Department of Public Health, in conjunction with the  
7 Governor's task force pursuant to Section 4 of the act  
8 amending this section, signed by the physician directing the  
9 care of the qualified minor, which when completed becomes the  
10 order directing all professional caregivers with respect to  
11 the extent of use of emergency medical equipment, medication,  
12 and any other technological interventions available to provide  
13 palliative and supportive care to the qualified minor.

14           "~~(15)~~ (17) PORTABLE PHYSICIAN DNAR ORDER. A DNAR  
15 order entered in the medical record by a physician using the  
16 required form designated by the State Board of Health and  
17 substantiated by completion of all sections of the form.

18           "(18) QUALIFIED MINOR. An individual ranging in age  
19 from birth until the age of 19 who has been diagnosed as  
20 terminally ill or injured. For purposes of this chapter, a  
21 qualified minor shall be considered an adult when acting  
22 through a qualified representative under this chapter only as  
23 permitted and set forth in this chapter.

24           "(19) QUALIFIED REPRESENTATIVE. Any of the following  
25 with regard to a qualified minor:

26           "a. A parent of a qualified minor whose medical  
27 decision making rights have not been restricted.

1           "b. A legal guardian of a qualified minor, which may  
2 include situations where the Department of Human Resources has  
3 custody of a minor.

4           "c. An adult acting in loco parentis on behalf of a  
5 qualified minor.

6           "~~(16)~~ (20) RESUSCITATIVE MEASURES. Those measures  
7 used to restore or support cardiac or respiratory function in  
8 the event of cardiopulmonary cessation.

9           "~~(17)~~ (21) SURROGATE. Any person appointed to act on  
10 behalf of an individual pursuant to Section 22-8A-11.

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

18           "§22-8A-7.

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

24           "(b) If the individual is not competent at the time  
25 of the decision to provide, withhold, or withdraw  
26 life-sustaining treatment or artificially provided nutrition  
27 and hydration, a living will executed in accordance with

1 Section 22-8A-4(a) or a proxy designation executed in  
2 accordance with Section 22-8A-4(b) is presumed to be valid.  
3 For the purpose of this chapter, a health care provider may  
4 presume in the absence of actual notice to the contrary that  
5 an individual who executed an advance directive for health  
6 care was competent when it was executed. The fact of an  
7 individual's having executed an advance directive for health  
8 care shall not be considered as an indication of a declarant's  
9 mental incompetency. Advanced age of itself shall not be a bar  
10 to a determination of competency.

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

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

4                   §22-8A-15.

5                   (a) For purposes of this chapter, a qualified  
6 representative may act on behalf of a qualified minor in the  
7 following circumstances:

8                   (1) Executing an advance directive for health care  
9 under Section 22-8A-4.

10                   (2) Consenting to a DNAR order under Section  
11 22-8A-4.1.

12                   (3) Revoking an advanced directive for health care  
13 pursuant to Section 22-8A-5.

14                   (4) Executing a palliative and end of life  
15 individual health plan pursuant to Section 22-8A-16.

16                   (5) Acting as a designated proxy under Section  
17 22-8A-6.

18                   (6) Acting as a surrogate under Section 22-8A-11.

19                   (b) A qualified representative shall have legal  
20 rights, duties, responsibilities, and obligations to act in a  
21 fiduciary capacity on behalf of a qualified minor.

22                   §22-8A-16.

23                   (a) As used in this section and Section 22-8A-17,  
24 school means any K-12 public school, charter school, any  
25 educational or correctional institution under the control of  
26 the Department of Youth Services, the Alabama Institute for

1 Deaf and Blind, the Alabama School of Fine Arts, and the  
2 Alabama School of Math and Science.

3 (b) As a prerequisite to executing any directives,  
4 orders, or guidance on behalf of a qualified minor regarding  
5 care and services in a school, a qualified representative  
6 shall complete a palliative and end of life individual health  
7 plan and file a copy of the plan with any school the qualified  
8 minor attends.

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

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

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

21 (2) A detailed listing of expectations of  
22 non-medical care as it applies to non-medical professionals  
23 and other individuals specifically addressing circumstances in  
24 anticipation of the death of the qualified minor.

25 (3) A detailed plan of action for the school in the  
26 event of a qualified minor's death while participating in a  
27 school activity, including guidance and plans for addressing

1 the needs of other children who may witness the death of the  
2 minor.

3 (4) A detailed plan of action for the school in the  
4 event of a qualified minor's death while on school property or  
5 at a school event, with regard to what should be done with the  
6 body of the qualified minor.

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

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

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

1           (8) An acknowledgement by the qualified  
2 representative that he or she has been provided information  
3 about the risks and benefits of the activities as described in  
4 the palliative and end of life individual health plan and how  
5 the activities may affect the death of the qualified minor.

6           (9) Any other requirement that may be established by  
7 rule in accordance with this chapter.

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

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

17           §22-8A-17.

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

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

12 §22-8A-18.

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

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

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

1 (b) The Governor shall appoint a task force, to  
2 serve for no more than two years under the supervision of the  
3 Alabama Department of Public Health, to establish the  
4 Physician Order for PPEL Care form. The task force shall  
5 include all of the following representatives:

6 (1) A representative of urban emergency medical  
7 services, appointed by the Governor.

8 (2) A representative of rural emergency medical  
9 services, appointed by the Governor.

10 (3) A pediatrician caring for medically complex  
11 children in an urban area, appointed by the Governor.

12 (4) A pediatrician caring for medically complex  
13 children in a rural area, appointed by the Governor.

14 (5) Two pediatric specialists from any of the  
15 following disciplines, appointed by the Governor: Oncology,  
16 cardiology, neurology, or pulmonology.

17 (6) A pediatric ethicist, appointed by the Governor.

18 (7) A nurse, appointed by the Alabama Board of  
19 Nursing.

20 (8) The Director for School Nurses of the State  
21 Department of Education, or his or her designee.

22 (9) The Director Child Care Facilities of the  
23 Department of Human Resources, or his or her designee.

24 (10) The State Health Officer, or his or her  
25 designee.

26 (11) A pediatric advanced practice practitioner,  
27 appointed by the Governor.

1 (12) Two social workers, appointed by the Governor.

2 (13) A representative of the Alabama Hospital  
3 Association appointed by the association.

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

6 (15) A representative of Children's and Women's  
7 Hospital at the University of South Alabama appointed by the  
8 hospital.

9 (16) A representative of the Alabama State Advisory  
10 Council on Palliative Care and Quality of Life appointed by  
11 the organization.

12 (17) A representative of the Medical Association of  
13 Alabama, appointed by the association.

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

16 (19) Two hospital chaplains appointed by the  
17 Governor.

18 (20) A pediatric palliative care physician,  
19 appointed by the Governor.

20 (21) A physician who practices hospital emergency  
21 medicine, appointed by the Governor.

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

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

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

3                   Section 5. This act shall become effective three  
4 months following its passage and approval by the Governor, or  
5 its otherwise becoming law.