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3 SUBSTITUTE FOR HB194
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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 authorize the physician of a
14 terminally ill or injured minor to execute, at the
15 request of the minor's parent or legal guardian, a
16 directive for the medical treatment and palliative
17 care to be provided to a terminally ill or injured
18 minor.

19 This bill would require the Department of
20 Public Health, by rule and in conjunction with a
21 task force, to establish a form for an Order for
22 Pediatric Palliative and End of Life (PPEL) Care to
23 be used by medical professionals outlining medical
24 care provided to a minor with a terminal illness.

25 This bill would provide immunity to health
26 care providers who provide, withhold, or withdraw

1 medical treatment pursuant to an Order for PPEL
2 Care.

3 This bill would also establish a temporary
4 task force to work in consultation with the
5 Department of Public Health to establish an Order
6 for Pediatric Palliative and End of Life (PPEL)
7 Care form.

8
9 A BILL
10 TO BE ENTITLED
11 AN ACT

12
13 Relating to terminally ill minors; to amend Sections
14 22-8A-2 and 22-8A-3, Code of Alabama 1975; to add Sections
15 22-8A-15 to 22-8A-17, inclusive, to the Code of Alabama 1975;
16 to create the Alex Hoover Act; to authorize the physician of a
17 terminally ill or injured minor to execute, at the request of
18 the minor's parent or legal guardian, a directive for the
19 medical treatment and palliative care to be provided to a
20 terminally ill or injured minor; to require the Department of
21 Public Health, by rule and in conjunction with a task force,
22 to establish a form for an Order for Pediatric Palliative and
23 End of Life (PPEL) Care to be used by medical professionals
24 outlining medical care provided to terminally ill minors in
25 certain circumstances; to provide immunity to health care
26 providers who provide, withhold, or withdraw medical treatment
27 pursuant to an Order for PPEL Care; and to establish a

1 temporary task force to work in consultation with the
2 Department of Public Health to establish an Order for
3 Pediatric Palliative and End of Life (PPEL) Care form.

4 BE IT ENACTED BY THE LEGISLATURE OF ALABAMA:

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

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

9 "§22-8A-2.

10 "(a) The Legislature finds that competent adult
11 persons have the right to control the decisions relating to
12 the rendering of their own medical care, including, without
13 limitation, the decision to have medical procedures,
14 life-sustaining treatment, and artificially provided nutrition
15 and hydration provided, withheld, or withdrawn in instances of
16 terminal conditions and permanent unconsciousness. In order
17 that the rights of individuals may be respected even after
18 they are no longer able to participate actively in decisions
19 about themselves, the Legislature hereby declares that the
20 laws of this state shall recognize the right of a competent
21 adult person to make a written declaration instructing ~~his or~~
22 ~~her physician~~ a health care provider to provide, withhold, or
23 withdraw life-sustaining treatment and artificially provided
24 nutrition and hydration or designate by lawful written form a
25 health care proxy to make decisions on behalf of the adult
26 person concerning the providing, withholding, or withdrawing
27 of life-sustaining treatment and artificially provided

1 nutrition and hydration in instances of terminal conditions
2 and permanent unconsciousness. The Legislature ~~further~~ desires
3 to provide for the appointment of surrogate decision-makers in
4 instances where the individual has not made such a
5 designation.

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

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

17 "§22-8A-3.

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

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

22 "(2) ARTIFICIALLY PROVIDED NUTRITION AND HYDRATION.

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

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

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

8 "(5) CARDIOPULMONARY CESSATION. A lack of pulse or
9 respiration.

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

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

1 proxy or surrogate functioning under the provisions in this
2 chapter; or instructions by an attorney in fact under a
3 durable power of attorney that duly grants powers to the
4 attorney in fact to make those decisions described in Section
5 22-8A-4(b) (1) .

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

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

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

1 "(11) LIVING WILL. A witnessed document in writing,
2 voluntarily executed by the declarant, that gives directions
3 and may appoint a health care proxy, in accordance with the
4 requirements of Section 22-8A-4.

5 "(12) ORDER FOR PEDIATRIC PALLIATIVE AND END OF LIFE
6 (PPEL) CARE. A form signed by the attending physician of a
7 qualified minor in consultation with the representative of the
8 qualified minor, which when executed becomes the medical order
9 for all health care providers with respect to the extent of
10 use of emergency medical equipment and treatment, medication,
11 and any other technological or medical interventions available
12 to provide palliative and supportive care to the qualified
13 minor.

14 "~~(12)~~ (13) PERMANENT UNCONSCIOUSNESS. A condition
15 that, to a reasonable degree of medical certainty:

16 "a. Will last permanently, without improvement; and

17 "b. In which cognitive thought, sensation,
18 purposeful action, social interaction, and awareness of self
19 and environment are absent; and

20 "c. Which condition has existed for a period of time
21 sufficient, in accordance with applicable professional
22 standards, to make such a diagnosis; and

23 "d. Which condition is confirmed by a physician who
24 is qualified and experienced in making such a diagnosis.

25 "~~(13)~~ (14) PERSON. An individual, corporation,
26 business trust, estate, trust, partnership, association, joint

1 venture, government, governmental subdivision or agency, or
2 any other legal or commercial entity.

3 "~~(14)~~ (15) PHYSICIAN. A person licensed to practice
4 medicine and osteopathy in the State of Alabama.

5 "~~(15)~~ (16) PORTABLE PHYSICIAN DNAR ORDER. A DNAR
6 order entered in the medical record by a physician using the
7 required form designated by the State Board of Health and
8 substantiated by completion of all sections of the form.

9 "(17) QUALIFIED MINOR. An individual ranging in age
10 from birth until the age of 19 who has been diagnosed as a
11 terminally ill or injured patient and whose diagnosis has been
12 confirmed by at least one additional physician who is not the
13 patient's attending physician.

14 "(18) REPRESENTATIVE OF A QUALIFIED MINOR. Any of
15 the following with regard to a qualified minor:

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

18 "b. A legal guardian of a qualified minor.

19 "c. A person acting as a parent, as the term is
20 defined in Section 30-3B-102.

21 "~~(16)~~ (19) RESUSCITATIVE MEASURES. Those measures
22 used to restore or support cardiac or respiratory function in
23 the event of cardiopulmonary cessation.

24 "~~(17)~~ (20) SURROGATE. Any person appointed to act on
25 behalf of an individual pursuant to Section 22-8A-11.

26 "~~(18)~~ (21) TERMINALLY ILL OR INJURED PATIENT. A
27 patient whose death is imminent or whose condition, to a

1 reasonable degree of medical certainty, is hopeless unless he
2 or she is artificially supported through the use of
3 life-sustaining procedures and which condition is confirmed by
4 a physician who is qualified and experienced in making such a
5 diagnosis."

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

8 §22-8A-15.

9 (a) A representative of a qualified minor shall have
10 reasonable legal rights, duties, responsibilities, and
11 obligations to act on behalf of the qualified minor. It is the
12 intent of this section to recognize the desires of a qualified
13 minor and of the representative of the qualified minor with
14 respect to the extent of medical treatment, medication, and
15 other interventions available to provide palliative and
16 supportive care to the qualified minor. A representative of a
17 qualified minor may request of the qualified minor's attending
18 physician that an Order for Pediatric Palliative and End of
19 Life (PPEL) Care be executed to carry out these desires.

20 (b) The Department of Public Health, in consultation
21 with the task force created pursuant to Section 22-8A-16,
22 shall adopt rules not later than March 31, 2019, establishing
23 the Order for PPEL Care form.

24 (c) The desires of a representative of a qualified
25 minor shall at all times supersede the effect of an Order for
26 PPEL Care executed in accordance with this section.

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

17 §22-8A-16.

18 (a) A task force is created to serve under the
19 supervision of the Alabama Department of Public Health, to
20 establish the Order for PPEL Care form. The task force shall
21 include all of the following representatives:

22 (1) One representative of urban emergency medical
23 services, appointed by the Governor.

24 (2) One representative of rural emergency medical
25 services, appointed by the Governor.

26 (3) One pediatrician caring for medically complex
27 children in an urban area, appointed by the Governor.

1 (4) One pediatrician caring for medically complex
2 children in a rural area, appointed by the Governor.

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

6 (6) One pediatric ethicist, appointed by the
7 Governor.

8 (7) One nurse, appointed by the Alabama Board of
9 Nursing.

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

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

14 (10) The State Health Officer, or his or her
15 designee.

16 (11) One pediatric certified registered nurse
17 practitioner, appointed by the Governor.

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

19 (13) One representative of the Alabama Hospital
20 Association, appointed by the association.

21 (14) One representative of Children's Hospital of
22 Alabama, appointed by the hospital.

23 (15) One representative of Children's and Women's
24 Hospital at the University of South Alabama, appointed by the
25 hospital.

1 (16) One representative of the Alabama State
2 Advisory Council on Palliative Care and Quality of Life,
3 appointed by the organization.

4 (17) One representative of the Medical Association
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.

8 (19) Two hospital chaplains, appointed by the
9 Governor.

10 (20) One pediatric palliative care physician,
11 appointed by the Governor.

12 (21) One physician who practices hospital emergency
13 medicine, appointed by the Governor.

14 (22) One emergency medicine physician who practices
15 at one of the Alabama licensed pediatric specialty hospitals,
16 appointed by the Governor.

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

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

21 (b) The appointing authorities shall coordinate
22 their appointments to assure the task force membership is
23 inclusive and reflects the racial, gender, geographic, urban,
24 rural, and economic diversity of the state.

25 (c) The State Health Officer, or his or her
26 designee, shall serve as chair of the task force.

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.

7 Section 4. Section 22-8A-17 is added to the Code of
8 Alabama 1975, to read as follows:

9 §22-8A-17.

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

15 Section 5. Section 22-8A-17 is added to the Code of
16 Alabama 1975, to read as follows:

17 §22-8A-17.

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

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