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3 SENATE HEALTH AND HUMAN SERVICES COMMITTEE SUBSTITUTE FOR
4 HB194, AS ENGROSSED

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9 SYNOPSIS: Under existing law, an adult or a health
10 care proxy for an adult may execute an advance
11 directive for health care or do not resuscitate
12 order.

13 This bill would create the Alex Hoover Act.

14 This bill would authorize the parent or
15 legal guardian of a terminally ill or injured minor
16 to execute, in consultation with the minor's
17 attending physician, a directive for the medical
18 treatment and palliative care to be provided to a
19 terminally ill or injured minor.

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

26 This bill would provide immunity to health
27 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.

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9 A BILL
10 TO BE ENTITLED
11 AN ACT
12

13 Relating to terminally ill minors; to amend Sections
14 22-8A-2, 22-8A-3, and 22-8A-7, Code of Alabama 1975; to add
15 Sections 22-8A-15 to 22-8A-17, inclusive, to the Code of
16 Alabama 1975; to create the Alex Hoover Act; to authorize the
17 parent or legal guardian of a terminally ill or injured minor
18 to execute, in consultation with the minor's attending
19 physician, a directive for the medical treatment and
20 palliative care to be provided to a terminally ill or injured
21 minor; to require the Department of Public Health, by rule and
22 in conjunction with a task force, to establish a form for an
23 Order for Pediatric Palliative and End of Life (PPEL) Care to
24 be used by medical professionals outlining medical care
25 provided to terminally ill minors in certain circumstances; to
26 provide immunity to health care providers who provide,
27 withhold, or withdraw medical treatment pursuant to an Order

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

5 BE IT ENACTED BY THE LEGISLATURE OF ALABAMA:

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

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

10 "§22-8A-2.

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

1 life-sustaining treatment and artificially provided nutrition
2 and hydration in instances of terminal conditions and
3 permanent unconsciousness. The Legislature further desires to
4 provide for the appointment of surrogate decision-makers in
5 instances where the individual has not made such a designation
6 and to allow a health care provider to follow certain portable
7 physician orders and orders for pediatric and palliative and
8 end of life care as provided for in this chapter.

9 "§22-8A-3.

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

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

14 "(2) ARTIFICIALLY PROVIDED NUTRITION AND HYDRATION.

15 A medical treatment consisting of the administration of food
16 and water through a tube or intravenous line, where the
17 recipient is not required to chew or swallow voluntarily.
18 Artificially provided nutrition and hydration does not include
19 assisted feeding, such as spoon or bottle feeding.

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

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

1 "(5) CARDIOPULMONARY CESSATION. A lack of pulse or
2 respiration.

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

7 "(7) DO NOT ATTEMPT RESUSCITATION (DNAR) ORDER. A
8 physician's order that resuscitative measures not be provided
9 to a person under a physician's care in the event the person
10 is found with cardiopulmonary cessation. A do not attempt
11 resuscitation order would include, without limitation,
12 physician orders written as "do not resuscitate," "do not
13 allow resuscitation," "do not allow resuscitative measures,"
14 "DNAR," "DNR," "allow natural death," or "AND." A do not
15 attempt resuscitation order must be entered with the consent
16 of the person, if the person is competent; or in accordance
17 with instructions in an advance directive if the person is not
18 competent or is no longer able to understand, appreciate, and
19 direct his or her medical treatment and has no hope of
20 regaining that ability; or with the consent of a health care
21 proxy or surrogate functioning under the provisions in this
22 chapter; or instructions by an attorney in fact under a
23 durable power of attorney that duly grants powers to the
24 attorney in fact to make those decisions described in Section
25 22-8A-4(b) (1) .

26 "(8) HEALTH CARE PROVIDER. A person who is licensed,
27 certified, registered, or otherwise authorized by the law of

1 this state to administer or provide health care in the
2 ordinary course of business or in the practice of a
3 profession.

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

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

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

25 "(12) ORDER FOR PEDIATRIC PALLIATIVE AND END OF LIFE
26 (PPEL) CARE. A directive that, once executed by the
27 representative of a qualified minor and entered into the

1 record by the attending physician of the qualified minor in
2 accordance with Section 22-8A-15, becomes the medical order
3 for all health care providers with respect to the extent of
4 use of emergency medical equipment and treatment, medication,
5 and any other technological or medical interventions available
6 to provide palliative and supportive care to the qualified
7 minor.

8 "~~(12)~~ (13) PERMANENT UNCONSCIOUSNESS. A condition
9 that, to a reasonable degree of medical certainty:

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

11 "b. In which cognitive thought, sensation,
12 purposeful action, social interaction, and awareness of self
13 and environment are absent; and

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

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

19 "~~(13)~~ (14) PERSON. An individual, corporation,
20 business trust, estate, trust, partnership, association, joint
21 venture, government, governmental subdivision or agency, or
22 any other legal or commercial entity.

23 "~~(14)~~ (15) PHYSICIAN. A person licensed to practice
24 medicine and osteopathy in the State of Alabama.

25 "~~(15)~~ (16) PORTABLE PHYSICIAN DNAR ORDER. A DNAR
26 order entered in the medical record by a physician using the

1 required form designated by the State Board of Health and
2 substantiated by completion of all sections of the form.

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

8 "(18) REPRESENTATIVE OF A QUALIFIED MINOR. Any of
9 the following:

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

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

13 "c. A person acting as a parent, as the term is
14 defined in Section 30-3B-102, of a qualified minor.

15 ~~"(16)~~ (19) RESUSCITATIVE MEASURES. Those measures
16 used to restore or support cardiac or respiratory function in
17 the event of cardiopulmonary cessation.

18 ~~"(17)~~ (20) SURROGATE. Any person appointed to act on
19 behalf of an individual pursuant to Section 22-8A-11.

20 ~~"(18)~~ (21) TERMINALLY ILL OR INJURED PATIENT. A
21 patient whose death is imminent or whose condition, to a
22 reasonable degree of medical certainty, is hopeless unless he
23 or she is artificially supported through the use of
24 life-sustaining procedures and which condition is confirmed by
25 a physician who is qualified and experienced in making such a
26 diagnosis.

27 "§22-8A-7.

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

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

20 "(c) No physician, licensed health care
21 professional, medical care facility, other health care
22 provider, or any employee thereof who in good faith and
23 pursuant to reasonable medical standards issues or follows a
24 portable physician DNAR order entered in the medical record
25 pursuant to this chapter or causes or participates in the
26 providing, withholding, or withdrawing of life-sustaining
27 treatment or artificially provided nutrition and hydration

1 from a patient pursuant to a living will or designated proxy
2 made in accordance with this chapter or pursuant to the
3 directions of a duly designated surrogate appointed in
4 accordance with this chapter, in the absence of actual
5 knowledge of the revocation thereof, shall, as a result
6 thereof, be subject to criminal or civil liability, or be
7 found to have committed an act of unprofessional conduct.

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

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

26 §22-8A-15.

1 (a) The representative of a qualified minor may
2 execute a directive with respect to the extent of medical
3 treatment, medication, and other interventions available to
4 provide palliative and supportive care to the qualified minor
5 by completing and signing an Order for PPEL Care form. Once
6 completed and signed by the representative, the attending
7 physician may complete and sign the executed directive and
8 enter the directive into the medical record of the qualified
9 minor. Once properly entered and received into the medical
10 record, the directive is deemed a valid Order for PPEL Care;
11 provided, however, it is the intent of this section to
12 recognize the desires as reflected in communications,
13 including verbal or written statements of a qualified minor
14 and of the representative of a qualified minor with respect to
15 the extent of medical treatment, medication, and other
16 interventions available to provide palliative and supportive
17 care to the qualified minor. The desires, as reflected in
18 communications, including verbal or written statements, of a
19 qualified minor and representative of a qualified minor shall
20 at all times supersede an Order for PPEL Care.

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

25 (c) The Department of Public Health may adopt rules
26 to implement this section.

27 §22-8A-16.

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

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

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

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

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

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

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

18 (7) One 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 of 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) One pediatric certified registered nurse
27 practitioner, appointed by the Governor.

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

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

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

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

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

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

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

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

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

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

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

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

9 (d) The first meeting of the task force shall be
10 held not later than June 1, 2018, at which time the task force
11 may appoint or elect a vice chair.

12 (e) The task force shall automatically terminate on
13 the date the rules establishing the Order for PPEL Care form
14 are adopted.

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

17 §22-8A-17.

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

23 (b) The attending physician of a qualified minor
24 shall have no supervisory authority over a school's execution
25 of a Palliative and End of Life Individual Health Plan. Any
26 health care provider or health care facility acting within the
27 applicable standard of care with regard to a Palliative and

1 End of Life Individual Health Plan is not subject to criminal
2 or civil liability and may not be found to have committed an
3 act of unprofessional conduct. Nothing in this act or any
4 related act involving Orders for PPEL Care shall be construed
5 to establish a standard of care for physicians or otherwise
6 modify, amend, or supersede any provisions of the Alabama
7 Medical Liability Act of 1987, the Alabama Medical Liability
8 Act of 1996, or any amendment or judicial interpretation
9 thereof.

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

12 §22-8A-17.

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

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