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3 HOUSE HEALTH COMMITTEE SUBSTITUTE FOR HB373  
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8 SYNOPSIS: Under existing law, an adult may execute an  
9 advance directive for health care.

10 This bill would create the Alex Hoover Act.

11 This bill would provide for portable medical  
12 orders to be created by the parent or guardian of a  
13 minor with a chronic or terminal illness, in  
14 consultation with the minor's treating physician,  
15 to guide health care professionals in medical  
16 treatment and guide others outside the medical  
17 community in allowing the minor to participate in  
18 school and other activities, in accordance with the  
19 wishes of the minor and his or her parents or  
20 guardians.

21 This bill would provide civil and criminal  
22 immunity to individuals, health care providers,  
23 health care facilities, and schools, who undertake  
24 to follow the directives of a portable medical  
25 order in good faith.

1                   This bill would also define terms and  
2                   provide procedures for executing portable medical  
3                   orders.

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5                   A BILL  
6                   TO BE ENTITLED  
7                   AN ACT

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9                   To create the Alex Hoover Act; relating to  
10                  chronically or terminally ill minors; to provide for portable  
11                  medical orders to be created by the parent or guardian of a  
12                  minor with a chronic or terminal illness, in consultation with  
13                  the minor's treating physician, to guide health care  
14                  professionals in medical treatment and guide others outside  
15                  the medical community in allowing the minor to participate in  
16                  school and other activities, in accordance with the wishes of  
17                  the minor and his or her parents or guardians; to provide  
18                  civil and criminal immunity to individuals, health care  
19                  providers, health care facilities, and schools, who undertake  
20                  to follow the directives of a portable medical order in good  
21                  faith; to create a working group appointed by the Alabama  
22                  State Advisory Council on Palliative Care and Quality of Life;  
23                  and to define terms and provide procedures for executing  
24                  portable medical orders.

25                  BE IT ENACTED BY THE LEGISLATURE OF ALABAMA:

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

1                   Section 2. It is the intent of this act to:

2                   (1) Recognize the needs, comfort, well-being, and  
3 dignity of a minor who is chronically or terminally ill as it  
4 relates to the health care provided to the minor and his or  
5 her ability to enjoy partaking in activities to the fullest  
6 extent possible.

7                   (2) Allow a parent or legal guardian of a  
8 chronically or terminally ill minor to execute a portable  
9 medical order to guide health care professionals in medical  
10 treatment, as well as those outside the medical community in  
11 allowing the minor to participate in school and other  
12 activities.

13                   Section 3. As used in this act, the following words  
14 shall have the following meanings:

15                   (1) CHRONIC OR TERMINAL ILLNESS. A condition or  
16 illness causing imminent death to a patient whose condition,  
17 to a reasonable degree of medical certainty, is hopeless  
18 unless he or she is artificially supported through the use of  
19 life-sustaining procedures and the condition is confirmed by a  
20 physician who is qualified and experienced in making such a  
21 diagnosis.

22                   (2) INDIVIDUAL HEALTH PLAN. A document that outlines  
23 health care to be provided to a student in the school setting,  
24 developed by the school nurse in conjunction with the  
25 student's parents or guardians and may contain the orders from  
26 the physician, certified registered nurse practitioner

1 operating under a valid collaborative agreement, or physician  
2 assistant operating with a valid supervisory agreement.

3 (3) MINOR. An individual ranging in age from birth  
4 until the age of 19. The term does not include an individual  
5 between 14 and 18 years of age who may legally give consent  
6 pursuant to Section 22-8-4, Code of Alabama 1975, and has the  
7 physical and mental capacity to give consent.

8 (4) PORTABLE MEDICAL ORDER (PMO). A directive  
9 executed by a representative or representatives of a  
10 chronically or terminally ill minor, along with the minor's  
11 treating physician, that details the medical treatment and  
12 expectations of care from medical professionals and others  
13 outside the medical community.

14 (5) REPRESENTATIVE. Either of the following:

15 a. The parent of a minor.

16 b. The legal guardian of a minor.

17 Section 4. (a) In addition to any order issued under  
18 Chapter 8A of Title 22, Code of Alabama 1975, the  
19 representative or representatives of a minor who has been  
20 diagnosed with a chronic or terminal illness, along with the  
21 minor's treating physician, may execute a portable medical  
22 order according to this section.

23 (b) A PMO form must be completed by a representative  
24 in consultation with the minor's physician, and the individual  
25 health plan shall be developed by the nurse in consultation  
26 with the parent or guardian. The individual health plan shall  
27 contain the medical orders and the PMO form. To the extent

1 possible depending on the age, maturity, and physical and  
2 mental ability to consent, the minor shall be consulted when  
3 completing the PMO form. The form shall contain all of the  
4 following information:

5 (1) The minor's medical history and prognosis.

6 (2) A range of appropriate medical treatment orders.

7 (3) Comfort measures.

8 (4) A narrative description of the minor's desires  
9 for participating in activities in the community, including  
10 activities at school during school hours and after school and  
11 any other organizations or activities in which the minor  
12 participates.

13 (5) The family's values and goals taking into  
14 consideration the desired quality of life of the minor, as  
15 developed in the individual health plan.

16 (c) A PMO is executed when the form is completed and  
17 signed and dated by all legal representatives of the minor and  
18 the treating physician.

19 (d) The representative shall keep the original  
20 executed PMO. The form shall be considered the personal  
21 property of the representative. The treating physician who  
22 executes the PMO form shall maintain a copy in the minor's  
23 medical records.

24 (e) An individual, health care provider, health care  
25 facility, school, organization, or other entity shall treat a  
26 facsimile, paper, or electronic copy of an executed PMO as an  
27 original document.

1 (f) A representative may revoke an executed PMO at  
2 any time by signing and dating a writing.

3 Section 5. (a) The medical orders and other  
4 directives included in a PMO executed under this act are  
5 effective in all settings.

6 (b) A health care provider or health care facility  
7 shall comply with the medical orders of an executed PMO that  
8 are apparent and immediately available to the provider.

9 (c) Outside of the medical community, a  
10 representative shall be responsible for providing individuals,  
11 schools, organizations, and other entities with a copy of an  
12 executed PMO. To the extent possible, a school, organization,  
13 or other entity shall follow the directives of an executed PMO  
14 when determining whether and to what extent the minor may  
15 participate in activities.

16 Section 6. (a) An individual, health care provider,  
17 health care facility, or school acting in good faith and in  
18 reasonable accordance with the directives in an executed PMO  
19 in compliance with this act is not subject to criminal or  
20 civil liability and may not be found to have committed an act  
21 of unprofessional conduct.

22 (b) An individual, health care provider, health care  
23 facility, school, organization, or an entity acting in good  
24 faith may not be considered to have knowledge of a PMO form  
25 solely on the basis of the PMO form's entry into a medical  
26 record.

1 (c) An individual who does not know, or should not  
2 reasonably know, that a PMO order exists, is not civilly or  
3 criminally liable for actions taken to assist a minor subject  
4 to a PMO form.

5 Section 7. (a) (1) The Alabama State Advisory Council  
6 on Palliative Care and Quality of Life shall appoint a working  
7 group representing interdisciplinary urban and rural pediatric  
8 practitioners, pediatric oncologists, pediatric ethics  
9 specialists, spiritual professionals, physician assistants  
10 with extensive pediatric experience, and pediatric certified  
11 registered nurse practitioners. The working group shall also  
12 include the Alabama State Department of Education State School  
13 Nurse Administrator, a representative of the Alabama Hospital  
14 Association, a licensed social worker with extensive work  
15 experience in pediatric practice, two school nurses  
16 representing the Alabama Association of School Nurses, and a  
17 patient and family caregiver advocate.

18 (2) The council shall coordinate its appointments to  
19 assure that the working group is inclusive and reflects the  
20 racial, gender, geographic, urban, rural, and economic  
21 diversity of the state.

22 (b) The working group shall meet not less frequently  
23 than on a monthly basis and, by December 31, 2017, shall  
24 develop a final form for a PMO for palliative and end of life  
25 care for minor individuals diagnosed with a chronic or  
26 terminal illness.

1                   Section 8. The Department of Public Health shall  
2                   adopt rules and a PMO form, pursuant to the Alabama  
3                   Administrative Procedure Act, for the implementation of this  
4                   act. In cooperation with the working group as set forth in  
5                   Section 7, the State Department of Education shall develop and  
6                   disseminate training materials for school nurses regarding the  
7                   development and implementation of individual health plans in  
8                   accordance with this act.

9                   Section 9. This act shall become effective on the  
10                  first day of the third month following its passage and  
11                  approval by the Governor, or its otherwise becoming law.