

Senate Bill 215

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SUMMARY

The following summary is not prepared by the sponsors of the measure and is not a part of the body thereof subject to consideration by the Legislative Assembly. It is an editor's brief statement of the essential features of the measure **as introduced**.

Directs Oregon Health Authority to establish and operate statewide database for collection and dissemination of orders for rare disease emergency response medical treatment for purpose of ensuring safe treatment of individuals with rare diseases in emergency situations. Creates Oregon ORDER Database Advisory Committee to advise authority on establishment, operation and evaluation of database.

A BILL FOR AN ACT

1
2 Relating to emergency response medical treatment necessary to treat a rare disease.

3 **Be It Enacted by the People of the State of Oregon:**

4 **SECTION 1. Definitions. As used in sections 1 to 8 of this 2017 Act:**

5 (1) **"Authorized user" means a person authorized by the Oregon Health Authority to**
6 **provide information to or receive information from the database established under section 2**
7 **of this 2017 Act.**

8 (2) **"Emergency response medical treatment" means an emergency medical procedure,**
9 **the emergency administration of a pharmaceutical or medical device or any other emergency**
10 **medical intervention that is necessary to prevent medical complications and maintain life.**

11 (3) **"Nurse practitioner" has the meaning given that term in ORS 678.010.**

12 (4) **"ORDER" means an order for rare disease emergency response medical treatment**
13 **that is necessary to treat a rare disease and that has been signed by a physician, nurse**
14 **practitioner or physician assistant.**

15 (5) **"Physician" has the meaning given that term in ORS 677.010.**

16 (6) **"Physician assistant" has the meaning given that term in ORS 677.495.**

17 (7) **"Rare disease" means a disease, disorder, allergy or mental health condition that, in**
18 **the professional judgment of a physician, nurse practitioner or physician assistant, is rare**
19 **and may require emergency response medical treatment.**

20 **SECTION 2. Establishment of database; rules. (1) The Oregon Health Authority shall es-**
21 **tablish and operate a statewide database for the collection and dissemination of orders for**
22 **rare disease emergency response medical treatment to ensure the safe treatment of indi-**
23 **viduals with rare diseases in emergency situations. The database must be available for use**
24 **by emergency medical service providers, hospitals, urgent care centers and the State Police.**

25 (2) **The authority shall adopt rules for the database established under subsection (1) of**
26 **this section, including rules that:**

27 (a) **Require the submission of the following documents to the database, unless the patient**
28 **has requested to opt out of the database:**

NOTE: Matter in **boldfaced** type in an amended section is new; matter *[italic and bracketed]* is existing law to be omitted. New sections are in **boldfaced** type.

- 1 (A) A copy of each ORDER;
- 2 (B) A copy of each revised ORDER; and
- 3 (C) Notice of each revocation of an ORDER;
- 4 (b) Prescribe the manner for submitting information to the database;
- 5 (c) Require the release of information from the database to authorized users;
- 6 (d) Provide notice by the database to authorized users of the receipt, revision or revo-
- 7 cation of an ORDER; and
- 8 (e) Establish procedures to protect the accuracy and confidentiality of information sub-
- 9 mitted to or released from the database.

10 (3) The authority may permit qualified researchers to access information kept in the
 11 database established under subsection (1) of this section. If the authority permits qualified
 12 researchers to access information under this subsection, the authority shall adopt rules
 13 governing that access, including rules that:

- 14 (a) Create a process by which a qualified researcher may request the access;
- 15 (b) Specify the types of information that may be accessed; and
- 16 (c) Establish the manner in which a qualified researcher must protect accessed infor-
- 17 mation.

18 (4) The authority may contract with a private or public entity to establish or maintain
 19 the database established under subsection (1) of this section. A contract entered into under
 20 this subsection is exempt from the requirements of ORS chapters 279A, 279B and 279C.

21 **SECTION 3. Oregon Health Authority not required to perform certain acts.** Nothing in
 22 sections 1 to 8 of this 2017 Act requires the Oregon Health Authority to:

- 23 (1) Prescribe the form or content of an ORDER;
- 24 (2) Disseminate forms to be used for an ORDER;
- 25 (3) Educate the public about ORDERS; or
- 26 (4) Train health care professionals about ORDERS.

27 **SECTION 4. ORDER not required; revocation.** (1) Nothing in sections 1 to 8 of this 2017
 28 Act requires:

- 29 (a) An individual to have an ORDER; or
- 30 (b) A health care professional to authorize or execute an ORDER.
- 31 (2) An ORDER may be revoked at any time.

32 **SECTION 5. Oregon ORDER Database Advisory Committee; members; meetings; term.**

33 (1) There is established within the Oregon Health Authority the Oregon ORDER Database
 34 Advisory Committee to advise the authority on the establishment, operation and evaluation
 35 of the database established under section 2 of this 2017 Act.

36 (2) The members of the committee shall be appointed by the Director of the Oregon
 37 Health Authority and shall include, at a minimum:

- 38 (a) A health care professional who has experience in ORDER issues;
- 39 (b) A physician who is a supervising physician, as defined in ORS 682.025, for emergency
 40 medical services providers, and who has experience in ORDER issues;
- 41 (c) A representative from the hospital community who has experience in ORDER issues;
- 42 (d) A representative from the rare disease and disorder community who has experience
 43 in ORDER issues;
- 44 (e) A representative from a rare disease or disorder patient group who has experience in
 45 ORDER issues;

1 (f) An emergency medical services provider actively involved in providing emergency
2 medical services; and

3 (g) Two members of the public who have an active interest in emergency response med-
4 ical treatment situations, at least one of whom represents the interests of minorities.

5 (3) The Director of the Emergency Medical Services and Trauma Systems Program
6 within the Oregon Health Authority, or a designee of the director, shall serve as a voting ex
7 officio member of the committee.

8 (4) The Director of the Oregon Health Authority may appoint additional members to the
9 committee.

10 (5) The committee shall meet at least four times per year, at times and places specified
11 by the Director of the Oregon Health Authority.

12 (6) Except for the member described in subsection (3) of this section, a member of the
13 committee shall serve a term of two years. Before the expiration of the term of a member,
14 the Director of the Oregon Health Authority shall appoint a successor whose term begins
15 on January 2 next following. A member is eligible for reappointment. If there is a vacancy
16 for any cause, the Director of the Oregon Health Authority shall make an appointment to
17 become immediately effective for the unexpired term.

18 (7) The Director of the Oregon Health Authority, or a designee of the director, shall
19 consult with the committee in drafting rules on the establishment, operation and evaluation
20 of the database established under section 2 of this 2017 Act.

21 **SECTION 6. Confidentiality.** Except as provided in section 2 of this 2017 Act, all infor-
22 mation kept in the database established under section 2 of this 2017 Act that identifies or
23 that could be used to identify a patient, health care professional or health care facility is
24 confidential and not subject to civil or administrative subpoena or to discovery in a civil or
25 administrative action.

26 **SECTION 7. Immunity from liability.** Any person reporting information to, or acting in
27 good faith on information released from, the database established under section 2 of this 2017
28 Act is immune from any civil or criminal liability that might otherwise be incurred or im-
29 posed with respect to the reporting of, or the acting on, the information.

30 **SECTION 8. Short title.** Sections 1 to 8 of this 2017 Act shall be known and may be cited
31 as the Oregon ORDER Database Act.

32 **SECTION 9. Initial term of membership for Oregon ORDER Database Advisory Commit-**
33 **tee.** Notwithstanding the term of office specified in section 5 of this 2017 Act, of the members
34 described in section 5 (2) of this 2017 Act who are first appointed to the Oregon ORDER
35 Database Advisory Committee:

36 (1) Four shall serve for terms ending January 1, 2019.

37 (2) The remaining members shall serve for terms ending January 1, 2020.

38 **SECTION 10. Captions.** The section captions used in this 2017 Act are provided only for
39 the convenience of the reader and do not become part of the statutory law of this state or
40 express any legislative intent in the enactment of this 2017 Act.

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