

By: Miles

S.B. No. 1641

A BILL TO BE ENTITLED

AN ACT

relating to the establishment of the Texas Rare Disease Advisory Council.

BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF TEXAS:

SECTION 1. Subtitle E, Title 2, Health and Safety Code, is amended by adding Chapter 101A to read as follows:

CHAPTER 101A. TEXAS RARE DISEASE ADVISORY COUNCIL

Sec. 101A.0001. DEFINITION. In this chapter, "advisory council" means the Texas Rare Disease Advisory Council established under this chapter.

Sec. 101A.0002. ESTABLISHMENT. (a) The department shall establish the Texas Rare Disease Advisory Council to advise the legislature, governor, and state agencies and private entities that provide services or care to individuals with rare diseases.

(b) The department shall designate a nonprofit organization operating in this state and with experience in the field of rare diseases to provide administrative support to the advisory council.

Sec. 101A.0003. INITIAL MEMBERS AND REPORT. (a) The governor or the governor's designee shall appoint the initial chair and vice chair of the advisory council.

(b) The chair and vice chair of the advisory council shall jointly appoint the other initial members of the advisory council.

(c) On appointment of all initial advisory council members, the advisory council shall develop and submit to the governor and

1 the legislature a written description of the intended mission of
2 the advisory council, including a list of any state agencies and
3 legislative committees that the advisory council intends to advise.

4 Sec. 101A.0004. TERMS; VACANCY. (a) Advisory council
5 members serve two-year terms.

6 (b) If a vacancy occurs on the advisory council, a person
7 shall be appointed to fill the vacancy for the unexpired term.

8 Sec. 101A.0005. MEMBERSHIP PROCEDURES. After initial
9 members are appointed under Section 101A.0003, the advisory council
10 shall determine the procedures for appointing members to the
11 advisory council provided that:

12 (1) the advisory council membership may not exceed 20
13 members;

14 (2) members appointed under this section must be
15 approved by a majority vote of the advisory council members;

16 (3) the advisory council may not modify a member's term
17 established under Section 101A.0004;

18 (4) members serve on the advisory council until
19 replaced; and

20 (5) a majority of advisory council members constitute
21 a quorum for purposes of conducting a meeting.

22 Sec. 101A.0006. DUTIES. The advisory council shall:

23 (1) advise the legislature, governor, and state
24 agencies and private entities that provide services or care to
25 individuals with rare diseases;

26 (2) coordinate with community-based organizations and
27 private entities in this state to ensure greater cooperation on

1 research, diagnosis, and treatment of rare diseases by:

2 (A) providing to the state agencies and private
3 entities the outcomes of the advisory council's research, best
4 practices, and policy recommendations; and

5 (B) using common research collection and
6 publication procedures;

7 (3) study and determine the most appropriate methods
8 for collecting information on rare diseases in this state and other
9 information the advisory council determines necessary and
10 appropriate to collect;

11 (4) study and identify priorities relating to the
12 quality, cost-effectiveness, and access to treatment and services
13 provided to individuals with rare diseases and develop related
14 policy recommendations;

15 (5) identify best practices for rare disease care
16 implemented by other state and federal agencies that may improve
17 rare disease care in this state;

18 (6) develop effective strategies to increase public
19 awareness of rare diseases in this state;

20 (7) ensure that the duties of the advisory council are
21 performed in a manner compatible with similar research conducted by
22 state and federal agencies; and

23 (8) develop a list of existing, publicly accessible
24 resources on research, diagnosis, treatment, and education
25 relating to rare diseases, in collaboration with medical schools,
26 public health schools, and hospitals in this state.

27 Sec. 101A.0007. REPORT. (a) The advisory council shall

1 prepare and submit a biennial report on the advisory council's
2 activities, findings, and recommendations to the governor,
3 department, and the standing committees of the senate and house of
4 representatives with primary jurisdiction over rare diseases.

5 (b) Not later than the 90th day after the date the report
6 described by Subsection (a) is received, the governor and
7 department shall provide a written response to the advisory council
8 on the governor's or department's efforts to improve state policies
9 on the identification, treatment, and care of individuals with rare
10 diseases.

11 (c) Not later than the 120th day after the date the report
12 described by Subsection (a) is received, the appropriate
13 legislative committees shall convene a hearing on the
14 identification of rare diseases and the treatment and care provided
15 to individuals with rare diseases.

16 Sec. 101A.0008. FUNDING. The advisory council may solicit
17 and accept gifts, grants, and donations to establish and operate
18 the advisory council.

19 Sec. 101A.0009. EXPIRATION; DONATION OF UNEXPENDED MONEY.
20 (a) This chapter expires and the advisory council is abolished
21 December 1, 2028.

22 (b) On abolishment, the advisory council shall donate any
23 unexpended money to an organization for improving the treatment and
24 care of individuals with rare diseases, including conducting
25 research on specific rare diseases.

26 SECTION 2. Not later than December 1, 2019, the governor
27 shall appoint the Texas Rare Disease Advisory Council members as

1 required by Chapter 101A, Health and Safety Code, as added by this
2 Act.

3 SECTION 3. This Act takes effect immediately if it receives
4 a vote of two-thirds of all the members elected to each house, as
5 provided by Section 39, Article III, Texas Constitution. If this
6 Act does not receive the vote necessary for immediate effect, this
7 Act takes effect September 1, 2019.