

By: Simmons

H.B. No. 3554

A BILL TO BE ENTITLED

AN ACT

relating to 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.001. DEFINITIONS. In this chapter:

(1) "Advisory council" means the Texas Rare Disease Advisory Council established under this chapter.

(2) "Rare disease" means a disease, disorder, or condition that affects fewer than 200,000 individuals in the United States.

Sec. 101A.002. ESTABLISHMENT. (a) The Texas Rare Disease Advisory Council is established to advise the governor, state agencies, and private entities that provide health care services or other treatment to individuals diagnosed with rare diseases in this state on strategies for improving health outcomes for those individuals.

(b) The department shall provide to the advisory council resources, personnel, and other administrative support as necessary for the council to carry out its duties under this chapter.

Sec. 101A.003. ADVISORY COUNCIL MEMBERS. (a) The advisory

1 council is composed of 23 members appointed as follows:

2 (1) 11 members appointed by the governor as follows:

3 (A) one representative of the department;

4 (B) one representative of the commission;

5 (C) one representative of the Texas Department of
6 Insurance;

7 (D) one representative of the Texas Education
8 Agency;

9 (E) one geneticist practicing in this state;

10 (F) one registered nurse or advanced practice
11 registered nurse licensed and practicing in this state with
12 experience in treating rare diseases;

13 (G) one hospital administrator of a hospital in
14 this state that provides care to individuals diagnosed with a rare
15 disease;

16 (H) one pharmacist licensed and practicing in
17 this state with experience dispensing prescription drugs used in
18 treating rare diseases;

19 (I) one representative of the biotechnology
20 industry;

21 (J) one representative of a health insurance
22 company; and

23 (K) one physician licensed and practicing in this
24 state with experience in treating rare diseases;

25 (2) six members appointed by the lieutenant governor
26 as follows:

27 (A) one representative of an academic research

1 institution in this state that receives grant funding for rare
2 disease research;

3 (B) one physician licensed and practicing in this
4 state with experience in treating rare diseases;

5 (C) one individual who is 18 years of age or older
6 and who is diagnosed with a rare disease;

7 (D) two individuals who are, or previously served
8 as, caregivers for an individual diagnosed with a rare disease; and

9 (E) one representative of an organization that
10 provides care or other support to individuals diagnosed with a rare
11 disease in this state; and

12 (3) six members appointed by the speaker of the house
13 of representatives as follows:

14 (A) one representative of an academic research
15 institution in this state that receives grant funding for rare
16 disease research;

17 (B) one physician licensed and practicing in this
18 state with experience in treating rare diseases;

19 (C) one individual who is 18 years of age or older
20 and who is diagnosed with a rare disease;

21 (D) two individuals who are, or previously served
22 as, caregivers for an individual diagnosed with a rare disease; and

23 (E) one representative of an organization that
24 provides care or other support to individuals diagnosed with a rare
25 disease in this state.

26 (b) Advisory council members serve staggered four-year
27 terms, with the terms of one-half of the members, or as near to

1 one-half as possible, expiring February 1 of each odd-numbered
2 year.

3 (c) A vacancy on the advisory council shall be filled for
4 the unexpired term in the same manner as the original appointment.

5 Sec. 101A.004. PRESIDING OFFICER; ASSISTANT PRESIDING
6 OFFICER. The governor shall annually select from among the
7 advisory council members a presiding officer and an assistant
8 presiding officer.

9 Sec. 101A.005. COUNCIL MEETINGS. (a) The advisory council
10 shall meet:

11 (1) at the call of the advisory council's presiding
12 officer; and

13 (2) on request by a majority of the advisory council
14 members.

15 (b) A majority of the voting members of the advisory council
16 constitutes a quorum.

17 (c) A meeting conducted under this section may be in person
18 or by video conference call, as determined by the advisory
19 council's presiding officer.

20 (d) The advisory council shall provide notice of upcoming
21 advisory council meetings on the department's Internet website.

22 Sec. 101A.006. DUTIES. (a) The advisory council shall:

23 (1) consult with experts on rare diseases and solicit
24 public comment to develop policy recommendations for improving the
25 treatment of rare diseases in this state;

26 (2) develop strategy recommendations for academic
27 research institutions of higher education in this state to

1 facilitate continued research on rare diseases;

2 (3) develop strategy recommendations for health care
3 providers to better recognize and diagnose rare diseases to improve
4 patient treatment; and

5 (4) make recommendations to the department and other
6 state agencies on matters affecting individuals diagnosed with a
7 rare disease, including emergency preparedness and response
8 resources for a pandemic or natural disaster.

9 (b) The advisory council shall provide the department with
10 the strategy recommendations developed under Subsection (a)(3) for
11 publication on the department's Internet website.

12 Sec. 101A.007. ANNUAL REPORT. (a) Not later than September
13 1 of each year, the advisory council shall prepare and submit to the
14 governor and commissioner a report that includes:

15 (1) a summary of the advisory council's activities for
16 the preceding year; and

17 (2) recommendations for legislative or other action on
18 rare disease research and care.

19 (b) The advisory council shall publish the report prepared
20 and submitted under Subsection (a) on the department's Internet
21 website.

22 Sec. 101A.008. APPLICABILITY OF OTHER LAW. Section
23 2110.008, Government Code, does not apply to the advisory council.

24 SECTION 2. Not later than December 1, 2025, the appropriate
25 appointing authority shall appoint the initial members to the Texas
26 Rare Disease Advisory Council as required by Section 101A.003(a),
27 Health and Safety Code, as added by this Act, with the initial

1 members' terms expiring as follows:

2 (1) the terms of five members appointed under Section
3 101A.003(a)(1), of three members appointed under Section
4 101A.003(a)(2), and of three members appointed under Section
5 101A.003(a)(3) expiring February 1, 2029; and

6 (2) the terms of six members appointed under Section
7 101A.003(a)(1), of three members appointed under Section
8 101A.003(a)(2), and of three members appointed under Section
9 101A.003(a)(3) expiring February 1, 2031.

10 SECTION 3. Notwithstanding Section 101A.005, Health and
11 Safety Code, as added by this Act, the Texas Rare Disease Advisory
12 Council shall conduct the council's first meeting not later than
13 January 1, 2026.

14 SECTION 4. Notwithstanding Section 101A.007, Health and
15 Safety Code, as added by this Act, the Texas Rare Disease Advisory
16 Council shall submit the first report required by that section not
17 later than September 1, 2026.

18 SECTION 5. This Act takes effect September 1, 2025.