

By: Miles

S.B. No. 1140

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) "Institution of higher education" means an institution of higher education or a private or independent institution of higher education, as those terms are defined by Section 61.003, Education Code.

Sec. 101A.002. ESTABLISHMENT OF ADVISORY COUNCIL. (a) The Texas Rare Disease Advisory Council is established to advise the legislature, the governor, state agencies, and private entities that provide services or care to individuals with rare diseases in this state on the needs of those individuals.

(b) The department shall designate an institution of higher education in this state on agreement of the institution to provide administrative support to the advisory council in discharging duties under this chapter.

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

1 council is composed of:

2 (1) one representative of the institution of higher  
3 education providing administrative support under Section 101A.002,  
4 appointed by the president of the institution;

5 (2) one representative of the department, appointed by  
6 the commissioner;

7 (3) one representative of the commission whose duties  
8 involve the medical assistance program under Chapter 32, Human  
9 Resources Code, appointed by the executive commissioner;

10 (4) one representative of the Texas Department of  
11 Insurance, appointed by the commissioner of insurance; and

12 (5) the following members, appointed by majority vote  
13 of the members of the advisory council described by Subdivisions  
14 (1)-(4):

15 (A) one geneticist licensed and practicing in  
16 this state;

17 (B) one registered nurse or advanced practice  
18 registered nurse licensed and practicing in this state with  
19 experience treating rare diseases;

20 (C) one physician licensed and practicing in this  
21 state with experience treating rare diseases;

22 (D) one hospital administrator, or the hospital  
23 administrator's designee, of a hospital in this state that provides  
24 care to persons diagnosed with a rare disease;

25 (E) at least two persons with a rare disease;

26 (F) at least one caregiver of a person with a rare  
27 disease;

1           (G) one representative of a rare disease patient  
2 organization that operates in this state;

3           (H) one pharmacist with experience dispensing  
4 drugs used to treat rare diseases;

5           (I) one representative of the biopharmaceutical  
6 industry;

7           (J) one representative of a health insurance  
8 company; and

9           (K) one member of the scientific community who is  
10 engaged in rare disease research, including a medical researcher  
11 with experience conducting research on rare diseases.

12           (a-1) Notwithstanding Subsection (a) and not later than  
13 December 1, 2025, the initial members of the advisory council shall  
14 be appointed as follows:

15           (1) the appropriate appointing authority shall  
16 appoint the members described by Subsections (a)(1)-(4); and

17           (2) the initial presiding officer of the advisory  
18 council appointed under Section 101A.004(b-1) shall appoint the  
19 members described by Subsection (a)(5).

20           (a-2) This subsection and Subsection (a-1) expire September  
21 1, 2031.

22           (b) Except as otherwise provided by Subsection (c), an  
23 individual must be a resident of this state to be eligible for  
24 appointment as a member of the advisory council.

25           (c) The representative of the biopharmaceutical industry  
26 appointed under Subsection (a)(5)(I) may be a resident of any  
27 state.

1 (d) If a vacancy occurs on the advisory council, the  
2 appropriate appointing authority shall, in a timely manner and in  
3 compliance with the requirements of this section, appoint a  
4 successor to serve for the remainder of the unexpired term.

5 (e) The advisory council shall conduct the member  
6 appointment process in a transparent manner to provide interested  
7 individuals an opportunity to apply for membership on the advisory  
8 council.

9 Sec. 101A.004. PRESIDING OFFICER. (a) Members of the  
10 advisory council shall select from among the advisory council's  
11 members a presiding officer.

12 (b) A person who holds an elected or appointed state  
13 governmental position or a state employee may not be appointed as  
14 the presiding officer of the advisory council.

15 (b-1) Notwithstanding Subsection (a) or Section 101A.005(b)  
16 and not later than October 1, 2025, the governor, or the governor's  
17 designee, shall appoint an initial presiding officer of the  
18 advisory council. This subsection expires September 1, 2031.

19 Sec. 101A.005. TERMS. (a) Members of the advisory council  
20 serve staggered three-year terms, with the terms of one-third of  
21 the members, or as near to one-third as possible, expiring each  
22 year.

23 (a-1) Notwithstanding Subsection (a), an initial advisory  
24 council member appointed under Section 101A.003(a-1) may serve a  
25 two-year, three-year, or four-year term. This subsection expires  
26 September 1, 2031.

27 (b) The presiding officer of the advisory council serves a

1 two-year term.

2 (b-1) Notwithstanding Subsection (b), the initial presiding  
3 officer of the advisory council appointed under Section  
4 101A.004(b-1) serves a three-year term. This subsection expires  
5 September 1, 2031.

6 Sec. 101A.006. DUTIES. The advisory council shall:

7 (1) consult with experts on rare diseases to develop  
8 policy recommendations for improving patient access to:

9 (A) rare disease specialists;

10 (B) affordable and comprehensive health care  
11 coverage;

12 (C) relevant diagnostic procedures for rare  
13 diseases;

14 (D) timely and quality treatment for rare  
15 diseases; and

16 (E) other needed services, as determined by the  
17 advisory council;

18 (2) make recommendations to state agencies and  
19 insurers that provide services to persons with a rare disease on the  
20 impact on treatment provision for the person of prior authorization  
21 requirements, cost-sharing requirements, benefits tiering, or  
22 other utilization management procedures;

23 (3) make recommendations to improve coverage under the  
24 state Medicaid program of drugs for rare disease patients,  
25 including engagement with the Drug Utilization Review Board, to  
26 improve health benefit plan coverage of diagnostic procedures, and  
27 to facilitate access to necessary health care providers with

1 expertise in the treatment of rare diseases;

2 (4) identify best practices to reduce health  
3 disparities and achieve health equity in the research, diagnosis,  
4 and treatment of rare diseases in this state; and

5 (5) identify best practices to ensure continuity of  
6 care for rare disease patients transitioning from pediatric to  
7 adult care.

8 Sec. 101A.007. BIENNIAL REPORT. (a) Not later than  
9 September 1 of each even-numbered year, the advisory council shall  
10 prepare and submit a report to the governor, department, and  
11 standing committees of the senate and house of representatives with  
12 primary jurisdiction over health care and appropriations a report  
13 on the advisory council's activities, funding, and legislative  
14 recommendations.

15 (b) Before finalizing and submitting the report under  
16 Subsection (a), a draft of the report must be made available for  
17 public comment and discussion at a meeting open to the public.

18 Sec. 101A.008. FUNDING. The advisory council may solicit  
19 and accept gifts, grants, and donations from any source to  
20 establish and operate the advisory council.

21 Sec. 101A.009. ADVISORY COUNCIL MEETINGS. (a) The  
22 advisory council shall meet at least once each quarter.

23 (b) A meeting conducted under this section may be in person  
24 or by video conference call, as determined by the presiding  
25 officer.

26 (c) Not later than January 1, 2026, the advisory council  
27 shall hold an initial meeting. During the 2026 calendar year, the

1 advisory council shall meet at least once per month. This  
2 subsection expires September 1, 2027.

3 Sec. 101A.010. PUBLIC OUTREACH. The advisory council  
4 shall:

5 (1) provide opportunities to inform the public about  
6 the advisory council's work and for the public to provide comments  
7 on that work; and

8 (2) create and maintain a public Internet website to:

9 (A) provide public access to meeting minutes;

10 (B) provide notice of upcoming advisory council  
11 meetings; and

12 (C) allow for the submission of public comments.

13 SECTION 2. This Act takes effect September 1, 2025.