

By: A. Johnson of Harris

H.B. No. 4619

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 on the needs of individuals with rare diseases in this state.

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

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

1 council is composed of the following members:

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

4 (2) one representative of the department;

5 (3) one representative of the commission whose duties  
6 involve the medical assistance program under Chapter 32, Human  
7 Resources Code;

8 (4) one representative of the Texas Department of  
9 Insurance;

10 (5) one geneticist licensed and practicing in this  
11 state;

12 (6) one registered nurse or advanced practice  
13 registered nurse licensed and practicing in this state with  
14 experience treating rare diseases;

15 (7) one physician licensed and practicing in this  
16 state with experience treating rare diseases;

17 (8) one hospital administrator, or the hospital  
18 administrator's designee, of a hospital in this state that provides  
19 care to persons diagnosed with a rare disease;

20 (9) at least two persons with a rare disease;

21 (10) at least one caregiver of a person with a rare  
22 disease;

23 (11) one representative of a rare disease patient  
24 organization that operates in this state;

25 (12) one pharmacist with experience dispensing drugs  
26 used to treat rare diseases;

27 (13) one representative of the biopharmaceutical

1 industry;

2 (14) one representative of a health insurance company;

3 and

4 (15) one member of the scientific community who is  
5 engaged in rare disease research, including a medical researcher  
6 with experience conducting research on rare diseases.

7 (a-1) Notwithstanding Subsection (a) and Section 101A.005  
8 and not later than December 1, 2023, the initial presiding officer  
9 of the advisory council appointed under Section 101A.004(b-1) shall  
10 appoint the initial members of the advisory council to staggered  
11 terms with the terms of one-third of the members, or as near to  
12 one-third as possible, expiring each year. An initial advisory  
13 council member appointed under this subsection may serve a  
14 two-year, three-year, or four-year term. This subsection expires  
15 September 1, 2029.

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

19 (c) The representative of the biopharmaceutical industry  
20 appointed under Subsection (a)(13) may be a resident of any state.

21 (d) If a vacancy occurs on the advisory council, the members  
22 of the advisory council shall fill the vacancy by a majority vote,  
23 in a timely manner and in compliance with the requirements of this  
24 section. The advisory council shall conduct the member appointment  
25 process in a transparent manner to provide interested individuals  
26 an opportunity to apply for membership on the advisory council.

27 Sec. 101A.004. PRESIDING OFFICER. (a) Members of the

1 advisory council shall select from among the advisory council's  
2 members a presiding officer.

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

6 (b-1) Notwithstanding Subsection (a) or Section 101A.005  
7 and not later than October 1, 2023, the governor, or the governor's  
8 designee, shall appoint an initial presiding officer of the  
9 advisory council to serve a three-year term. This subsection  
10 expires September 1, 2027.

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

15 (b) The presiding officer of the advisory council serves a  
16 two-year term.

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

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

20 (A) rare disease specialists;

21 (B) affordable and comprehensive health care  
22 coverage;

23 (C) relevant diagnostic procedures for rare  
24 diseases;

25 (D) timely and quality treatment for rare  
26 diseases; and

27 (E) other needed services, as determined by the

1 advisory council;

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

7 (3) make recommendations to improve coverage under the  
8 state Medicaid program of drugs for rare disease patients,  
9 including engagement with the Drug Utilization Review Board, to  
10 improve health benefit plan coverage of diagnostic procedures, and  
11 to facilitate access to necessary health care providers with  
12 expertise in the treatment of rare diseases;

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

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

19 Sec. 101A.007. BIENNIAL REPORT. (a) Not later than  
20 September 1 of each even-numbered year, the advisory council shall  
21 prepare and submit a report to the governor, department, and  
22 standing committees of the senate and house of representatives with  
23 primary jurisdiction over health care and appropriations a report  
24 on the advisory council's activities, funding, and legislative  
25 recommendations.

26 (b) Before finalizing and submitting the report under  
27 Subsection (a), a draft of the report must be made available for

1 public comment and discussion at an open public meeting.

2 Sec. 101A.008. FUNDING. The advisory council may solicit  
3 and accept gifts, grants, and donations to establish and operate  
4 the advisory council.

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

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

10 (c) Not later than January 1, 2024, the advisory council  
11 shall hold an initial meeting. During the 2024 calendar year, the  
12 advisory council shall meet at least once per month. This  
13 subsection expires September 1, 2025.

14 Sec. 101A.010. PUBLIC OUTREACH. The advisory council  
15 shall:

16 (1) provide opportunities to inform the public about  
17 the advisory council's work and for the public to provide comments  
18 on that work; and

19 (2) create and maintain a public Internet website to:  
20 (A) provide public access to meeting minutes;  
21 (B) provide notice of upcoming advisory council  
22 meetings; and

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

24 SECTION 2. (a) Not later than October 1, 2023, the governor  
25 or the governor's designee shall appoint the initial presiding  
26 officer to the Texas Rare Disease Advisory Council as required by  
27 Section 101A.004, Health and Safety Code, as added by this Act.

1           (b) Not later than December 1, 2023, the initial presiding  
2 officer of the Texas Rare Disease Advisory Council shall appoint  
3 the initial members of the advisory council as required by Section  
4 101A.003, Health and Safety Code, as added by this Act.

5           SECTION 3. This Act takes effect September 1, 2023.