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By:  Miles S.B. No. 1408

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 council is composed of the following members:

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

(2)  one representative of the department;

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

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

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

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

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

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

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

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

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

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

(13)  one representative of the biopharmaceutical industry;

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

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

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

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

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

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

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

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

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

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

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

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

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

(A)  rare disease specialists;

(B)  affordable and comprehensive health care coverage;

(C)  relevant diagnostic procedures for rare diseases;

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

(A)  provide public access to meeting minutes;

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

(C)  allow for the submission of public comments.

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

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

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