By: Miles S.B. No. 352

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 101B to read as follows:

CHAPTER 101B. TEXAS RARE DISEASE ADVISORY COUNCIL

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

council is composed of:

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

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

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

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

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

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

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

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

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

(E) at least two individuals with a rare disease;

(F) at least one caregiver of an individual with a rare disease;

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

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

(I) one representative of the biopharmaceutical industry;

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

(K) 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 not later than December 1, 2027, the initial members of the advisory council shall be appointed as follows:

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

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

(a-2) This subsection and Subsection (a-1) expire September 1, 2033.

(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)(5)(I) may be a resident of any state.

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

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

(b) An individual 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 101B.005(b) and not later than October 1, 2027, the governor, or the governor's designee, shall appoint an initial presiding officer of the advisory council. This subsection expires September 1, 2033.

Sec. 101B.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.

(a-1) Notwithstanding Subsection (a), an initial advisory council member appointed under Section 101B.003(a-1) may serve a two-year, three-year, or four-year term. This subsection expires September 1, 2033.

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

two-year term.

(b-1) Notwithstanding Subsection (b), the initial presiding officer of the advisory council appointed under Section 101B.004(b-1) serves a three-year term. This subsection expires September 1, 2033.

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

(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 a meeting open to the public.

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

Sec. 101B.009. ADVISORY 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, 2028, the advisory council shall hold an initial meeting. During the 2028 calendar year, the

advisory council shall meet at least once per month. This subsection expires September 1, 2029.

Sec. 101B.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. This Act takes effect September 1, 2027.