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1 C. The Council shall conduct the following activities to
2 benefit those impacted by rare diseases in this state:

3 1. Convene public hearings, make inquiries, and solicit
4 comments from the general public in Oklahoma to assist the Council
5 with a first-year landscape or survey of the needs of rare disease
6 patients, caregivers, and providers in the state;

7 2. Provide testimony and comments on pending legislation and
8 regulations before the Legislature, if called, and other state
9 agencies that impact Oklahoma's rare disease community;

10 3. Consult with experts on rare diseases to develop policy
11 recommendations to improve patient access to, and quality of, rare
12 disease specialists, affordable and comprehensive health care
13 coverage, relevant diagnostics, timely treatment, and other needed
14 services;

15 4. Establish best practices and protocols to include in state
16 planning related to natural disasters, public health emergencies, or
17 other emergency declarations to enable continuity of care for rare
18 disease patients and ensure safeguards against discrimination for
19 rare disease patients are in place;

20 5. Identify areas of unmet need for research and opportunities
21 for collaboration with stakeholders and other states' rare disease
22 advisory councils that can inform future studies and work done by
23 the Council; and
24

1 6. Research and identify best practices to reduce health
2 disparities and achieve health equity in the research, diagnosis,
3 and treatment of rare disease in this state.

4 D. 1. The Council's appointment process shall be conducted in
5 a transparent manner to provide interested individuals an
6 opportunity to apply for membership on the Council. All members of
7 the Council shall be full-time residents of this state as
8 practicable. Membership shall include a diverse set of stakeholders
9 representative of the geographic and population diversity of the
10 state.

11 2. The Governor shall appoint the chair of the Council not
12 later than December 1, 2025. The chair shall not hold any position
13 within the government of this state.

14 3. The chair shall appoint no fewer than thirteen (13) members,
15 including the following:

- 16 a. one representative of an academic research institution
17 in the state that receives any grant funding for rare
18 disease research,
- 19 b. one representative of the Oklahoma Health Care
20 Authority,
- 21 c. one representative of the Insurance Department,
- 22 d. one Registered Nurse or Advanced Practice Registered
23 Nurse licensed and practicing in this state with
24 experience treating rare diseases,

- e. one physician practicing in this state with experience treating rare diseases,
- f. one hospital administrator, or his or her designee, from a hospital in this state that provides care to persons diagnosed with a rare disease,
- g. at least two patients who have a rare disease,
- h. at least one caregiver of a person with a rare disease,
- i. one representative of a rare disease patient organization that operates in this state,
- j. one representative of the biopharmaceutical industry,
- k. one representative of a health plan company, and
- l. one member of the scientific community who is engaged in rare disease research including, but not limited to, a medical researcher with experience conducting research on rare diseases.

4. The chair may appoint additional members on an ad hoc basis.

E. 1. The Council shall electronically submit a report to the President Pro Tempore of the Senate, the Speaker of the House of Representatives, and the Governor within one (1) year of establishment of the Oklahoma Rare Disease Advisory Council and annually thereafter. Prior to submission, a draft of the annual report shall be made available for public comment and discussed at an open public meeting.

1 2. Annual reports shall:

2 a. describe the activities and progress of the Council
3 under this section, and

4 b. provide recommendations to the Legislature and
5 Governor on ways to address the needs of people living
6 with rare diseases in this state.

7 F. 1. The initial meeting of the Council shall occur no later
8 than February 1, 2026. Thereafter, the Council shall meet no less
9 than quarterly.

10 2. Meetings of the Council shall be conducted in accordance
11 with the Oklahoma Open Meeting Act.

12 G. The Council shall:

13 1. Provide opportunities for the public to hear updates and
14 provide input into its work; and

15 2. Create and maintain a public website where meeting minutes,
16 notices of upcoming meetings, and public comments may be submitted.

17 H. 1. The Governor shall appoint the chair for an initial term
18 of three (3) years. At the end of the chair's initial three-year
19 term, and every two (2) years thereafter, members of the Council
20 shall elect, by a majority vote, a new chair.

21 2. Council members shall serve no longer than three (3) years,
22 except that, to facilitate a staggered rotation of members to retain
23 continuity and knowledge transfer, during the initial five (5) years
24

1 after the establishment of the Council, members may serve up to a
2 four-year term.

3 3. If a vacancy occurs, the Council, by a majority vote, shall
4 fill such vacancy in a timely manner and in compliance with
5 requirements set forth in subsection D of this section.

6 I. As used in this section, "rare disease", sometimes called an
7 orphan disease, means a disease that affects fewer than two hundred
8 thousand (200,000) people in the United States.

9 SECTION 2. AMENDATORY 63 O.S. 2021, Section 1-533, as
10 amended by Section 1, Chapter 161, O.S.L. 2022 (63 O.S. Supp. 2024,
11 Section 1-533), is amended to read as follows:

12 Section 1-533. A. The State Commissioner of Health shall
13 provide, pursuant to the provisions of Section 1-534 of this title,
14 as technologies and funds become available, an intensive educational
15 and newborn screening program among physicians, hospitals, public
16 health nurses, and the public concerning phenylketonuria, related
17 inborn metabolic disorders, and other genetic or biochemical
18 disorders for which:

19 1. Newborn screening will provide early treatment and
20 management opportunities that might not be available without
21 screening; and

22 2. Treatment and management will prevent intellectual
23 disabilities and/or reduce infant morbidity and mortality.
24

1 B. This educational and newborn screening program shall include
2 information about:

- 3 1. The nature of the diseases;
- 4 2. Examinations for the detection of the diseases in infancy;
- 5 and
- 6 3. Follow-up measures to prevent the morbidity and mortality
- 7 resulting from these diseases.

8 C. For purposes of this section, "phenylketonuria" means an
9 inborn error of metabolism attributable to a deficiency of or a
10 defect in phenylalanine hydroxylase, the enzyme that catalyzes the
11 conversion of phenylalanine to tyrosine. The deficiency permits the
12 accumulation of phenylalanine and its metabolic products in the body
13 fluids. The deficiency can result in intellectual disabilities
14 (phenylpyruvic oligophrenia), neurologic manifestations (including
15 hyperkinesia, epilepsy, and microcephaly), light pigmentation, and
16 eczema. The disorder is transmitted as an autosomal recessive trait
17 and can be treated by administration of a diet low in phenylalanine.

18 D. To the extent practicable, the ~~list of~~ disorders screened
19 for under this section shall ~~be identical to~~ at a minimum include
20 those listed in the Recommended Uniform Screening Panel of the
21 United States Department of Health and Human Services.

22 E. On November 1, 2026, and each November 1 thereafter, the
23 State Department of Health shall compile an annual report listing
24 the disorders screened for under this section, specifying any

1 disorders added since the prior annual report, and detailing efforts
2 being undertaken to add additional disorders. The report shall be
3 published on the Department's website and shall be submitted
4 electronically to the President Pro Tempore of the Senate, the
5 Speaker of the House of Representatives, the Governor, and the
6 Oklahoma Rare Disease Advisory Council established under Section 1
7 of this act.

8 F. The Commissioner shall promulgate any rules necessary to
9 effectuate the provision of this section.

10 SECTION 3. This act shall become effective July 1, 2025.

11 SECTION 4. It being immediately necessary for the preservation
12 of the public peace, health or safety, an emergency is hereby
13 declared to exist, by reason whereof this act shall take effect and
14 be in full force from and after its passage and approval.

15
16 COMMITTEE REPORT BY: COMMITTEE ON HEALTH AND HUMAN SERVICES
17 OVERSIGHT, dated 04/23/2025 - DO PASS, As Amended and Coauthored.
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