STATE OF OKLAHOMA

1st Session of the 60th Legislature (2025)

SENATE BILL 207 By: Woods

AS INTRODUCED

An Act relating to public health; establishing the Oklahoma Rare Disease Advisory Council; stating purpose and activities of the Council; providing appointment procedures and membership requirements; requiring submission of certain annual report; prescribing certain meeting requirements; specifying duration of membership terms; providing for filling of vacancies; defining term; amending 63 O.S. 2021, Section 1-533, as amended by Section 1, Chapter 161, O.S.L. 2022 (63 O.S. Supp. 2024, Section 1-533), which relates to educational and newborn screening programs; modifying certain screening requirement; requiring compilation and publication of certain annual report; creating the Newborn Screening Revolving Fund; specifying type of fund and source of monies; providing for expenditure of funds; providing for codification; providing an effective date; and declaring an emergency.

BE IT ENACTED BY THE PEOPLE OF THE STATE OF OKLAHOMA:

SECTION 1. NEW LAW A new section of law to be codified in the Oklahoma Statutes as Section 1-451 of Title 63, unless there is created a duplication in numbering, reads as follows:

A. The Oklahoma Rare Disease Advisory Council shall be established within the State Department of Health in accordance with this section.

B. The purpose of the Council shall be to provide guidance and recommendations to educate the public, the Legislature, and other state agencies, as appropriate, on the needs of individuals with rare diseases living in this state.

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

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

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

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

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

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

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

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

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

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

   a. one representative of an academic research institution in the state that receives any grant funding for rare disease research,

   b. one representative of the Oklahoma Health Care Authority,

c. one representative of the Insurance Department,

d. one Registered Nurse or Advanced Practice Registered Nurse licensed and practicing in this state with 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.

2. Annual reports shall:

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

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

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

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

G. The Council shall:

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

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

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

2. Council members shall serve no longer than three (3) years, except that, to facilitate a staggered rotation of members to retain continuity and knowledge transfer, during the initial five (5) years after the establishment of the Council, members may serve up to a four-year term.

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

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

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

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

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

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

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

1. The nature of the diseases;

2. Examinations for the detection of the diseases in infancy; and

3. Follow-up measures to prevent the morbidity and mortality resulting from these diseases.

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

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

E. On November 1, 2026, and each November 1 thereafter, the State Department of Health shall compile an annual report listing the disorders screened for under this section, specifying any disorders added since the prior annual report, and detailing efforts being undertaken to add additional disorders. The report shall be published on the Department's website and shall be submitted electronically to the President Pro Tempore of the Senate, the Speaker of the House of Representatives, the Governor, and the Oklahoma Rare Disease Advisory Council established under Section 1 of this act.

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

SECTION 3. NEW LAW A new section of law to be codified in the Oklahoma Statutes as Section 1-533.1 of Title 63, unless there is created a duplication in numbering, reads as follows:

There is hereby created in the State Treasury a revolving fund for the State Department of Health to be designated the "Newborn Screening Revolving Fund". The fund shall be a continuing fund, not subject to fiscal year limitations, and shall consist of all monies received by the Department from appropriations provided for the purpose of conducting newborn screening under Section 1-533 of Title 63 of the Oklahoma Statutes. All monies accruing to the credit of the fund are hereby appropriated and may be budgeted and expended by the Department for the purpose provided for in this section.

Expenditures from the fund shall be made upon warrants issued by the State Treasurer against claims filed as prescribed by law with the Director of the Office of Management and Enterprise Services for approval and payment.

SECTION 4. This act shall become effective July 1, 2025.

SECTION 5. It being immediately necessary for the preservation of the public peace, health or safety, an emergency is hereby declared to exist, by reason whereof this act shall take effect and be in full force from and after its passage and approval.

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