

1 STATE OF OKLAHOMA

2 1st Session of the 60th Legislature (2025)

3 HOUSE BILL 1019

By: McCane

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6 AS INTRODUCED

7 An Act relating to public health; establishing the
8 Oklahoma Rare Disease Advisory Council; stating
9 purpose and activities of the Council; providing
10 appointment procedures and membership requirements;
11 requiring submission of certain annual report;
12 specifying duration of membership terms; providing
13 for filling of vacancies; defining term; providing
14 for codification; and providing an effective date.

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

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

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

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

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 across stakeholders and other state rare disease
22 advisory councils that can inform future studies and work done by
23 the Council; and
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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 seventeen (17)
15 members, 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 State Department of Health's
20 Office of Minority Health and Health Equity, or
21 successor division,

22 c. one representative of the Oklahoma Health Care
23 Authority,

24 d. one representative of the Insurance Department,
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- 1 e. one registered nurse or Advanced Practice Registered
2 Nurse licensed and practicing in this state with
3 experience treating rare diseases,
4 f. one physician practicing in this state with experience
5 treating rare diseases,
6 g. one geneticist or genetic counselor,
7 h. one hospital administrator, or his or her designee,
8 from a hospital in this state that provides care to
9 persons diagnosed with a rare disease,
10 i. at least two patients who have a rare disease,
11 j. at least one caregiver of a person with a rare
12 disease,
13 k. one representative of a rare disease patient
14 organization that operates in this state,
15 l. one pharmacist with experience dispensing drugs used
16 to treat rare diseases,
17 m. one representative of the biopharmaceutical industry,
18 n. one representative of a health plan company,
19 o. one member of the scientific community who is engaged
20 in rare disease research including, but not limited
21 to, a medical researcher with experience conducting
22 research on rare diseases, and
23 p. one mental health provider with experience treating
24 rare disease patients in this state.
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1 E. 1. The Council shall electronically submit a report to the
2 President Pro Tempore of the Oklahoma State Senate, the Speaker of
3 the Oklahoma House of Representatives, and the Governor within one
4 (1) year of establishment of the Oklahoma Rare Disease Advisory
5 Council and annually thereafter. Prior to submission, a draft of
6 the annual report shall be made available for public comment and
7 discussed at an open public meeting.

8 2. The annual reports shall:

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

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

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

17 2. The Council shall:

18 a. provide opportunities for the public to hear updates
19 and provide input into its work, and

20 b. create and maintain a public website where meeting
21 minutes, notices of upcoming meetings, and public
22 comments may be submitted.

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

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

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

11 H. As used in this section, "rare disease", sometimes called an
12 orphan disease, means a disease that affects fewer than two hundred
13 thousand (200,000) people in the United States.

14 SECTION 2. This act shall become effective November 1, 2025.

16 60-1-11095 TJ 12/13/24