

COMMITTEE AMENDMENT
HOUSE OF REPRESENTATIVES
State of Oklahoma

SPEAKER:

CHAIR:

I move to amend HB1019 _____
Of the printed Bill
Page _____ Section _____ Lines _____
Of the Engrossed Bill

By deleting the content of the entire measure, and by inserting in lieu thereof the following language:

AMEND TITLE TO CONFORM TO AMENDMENTS

Adopted: _____

Amendment submitted by: Michelle McCane _____

Reading Clerk

1 STATE OF OKLAHOMA

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

3 PROPOSED SUBCOMMITTEE
4 SUBSTITUTE
5 FOR
6 HOUSE BILL NO. 1019

By: McCane

7
8 PROPOSED SUBCOMMITTEE SUBSTITUTE

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

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

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

22 A. There is hereby created within the State Department of
23 Health the Oklahoma Rare Disease Advisory Council.

24 B. The purpose of the Council shall be to provide guidance and
recommendations to educate the public, the Legislature, and other

1 state agencies, as appropriate, on the needs of individuals with
2 rare diseases living in this state.

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

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

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

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

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

22 5. Identify areas of unmet need for research and opportunities
23 for collaboration across stakeholders and other state rare disease
24

1 advisory councils that can inform future studies and work done by
2 the Council; and

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

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

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

16 3. The Governor shall appoint seven (7) members:

- 17 a. two patients who have a rare disease,
- 18 b. two caregivers of a person with a rare disease,
- 19 c. one representative of the biopharmaceutical industry,
- 20 d. one representative of a rare disease patient
21 organization that operates in this state, and
- 22 e. one representative of a health plan company.

23 4. The State Department of Health shall appoint five (5)
24 members:

- a. one representative of the State Department of Health's Office of Minority Health and Health Equity, or successor division,
- b. one registered nurse or Advanced Practice Registered Nurse licensed and practicing in this state with experience treating rare diseases,
- c. one physician practicing in this state with experience treating rare diseases,
- d. one pharmacist with experience dispensing drugs used to treat rare diseases, and
- e. 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.

5. The Oklahoma Health Care Authority shall appoint two (2) members:

- a. one representative of the Oklahoma Health Care Authority, and
- b. one geneticist or genetic counselor.

6. The Department of Mental Health and Substance Abuse Services shall appoint one member who is a mental health provider with experience treating rare disease patients in this state.

7. The State Regents for Higher Education shall appoint one member who is a representative of an academic research institution

1 in the state that receives any grant funding for rare disease
2 research.

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

10 2. The annual reports shall:

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

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

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

19 2. The Council shall:

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

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

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

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

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

13 H. As used in this section, "rare disease", also known as an
14 orphan disease, means a disease that affects fewer than two hundred
15 thousand (200,000) people in the United States.

16 I. The members of the Council shall be paid a per diem in
17 accordance with the State Travel Reimbursement Act when attending
18 Council meetings or other activities associated with the duties of
19 the Council members.

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

21

22 60-1-12482 TJ 02/13/25

23

24