

Representative Lee B. Perry proposes the following substitute bill:

RARE DISEASE ADVISORY COUNCIL

2019 GENERAL SESSION

STATE OF UTAH

Chief Sponsor: Lee B. Perry

Senate Sponsor: Luz Escamilla

LONG TITLE

General Description:

This bill creates the Rare Disease Advisory Council within the Department of Health.

Highlighted Provisions:

This bill:

- ▶ defines terms;
- ▶ creates the Rare Disease Advisory Council within the Department of Health;
- ▶ describes the composition and duties of the council; and
- ▶ establishes a review and sunset date for the council.

Money Appropriated in this Bill:

None

Other Special Clauses:

None

Utah Code Sections Affected:

AMENDS:

63I-1-226, as last amended by Laws of Utah 2018, Third Special Session, Chapter 1

ENACTS:

26-1-41, Utah Code Annotated 1953



26 *Be it enacted by the Legislature of the state of Utah:*

27 Section 1. Section **26-1-41** is enacted to read:

28 **26-1-41. Rare Disease Advisory Council -- Creation -- Purpose and duties.**

29 (1) As used in this section:

30 (a) "Council" means the Rare Disease Advisory Council created in this section.

31 (b) "Rare disease" means a disease that affects fewer than 200,000 individuals in the
 32 United States.

33 (2) There is created within the department, in coordination with the University of Utah,
 34 the Rare Disease Advisory Council.

35 (3) The purpose of the council is to:

36 (a) advise the Legislature and state agencies on providing services and care to
 37 individuals with a rare disease;

38 (b) make recommendations to the Legislature and state agencies on improving access
 39 to treatment and services provided to individuals with a rare disease; and

40 (c) identify best practices to improve the care and treatment of individuals in the state
 41 with a rare disease.

42 (4) The council shall:

43 (a) meet at least two times in each calendar year; and

44 (b) be composed of:

45 (i) members appointed by the executive director; and

46 (ii) at least the following individuals:

47 (A) a representative from the department;

48 (B) researchers and ~~H→~~ **health-care practitioners** **physicians** ~~←H~~ who specialize in rare
 48a diseases ~~H→~~ , **including at least one representative from the University of Utah** ~~←H~~ ;

49 (C) two individuals who are the ~~H→~~ **patient**, ~~←H~~ parent ~~H→~~ , ~~←H~~ or caregiver of an
 49a individual with a rare disease;

50 and

51 (D) two representatives from rare disease patient organizations that operate in the state.

52 (5) (a) The department shall provide staff and other administrative support to the
 53 council.

54 (b) A member of the council may not receive compensation or benefits for the
 55 member's service, but, at the director's discretion, may receive per diem and travel expenses in
 56 accordance with Sections [63A-3-106](#) and [63A-3-107](#).

57 (6) Before November 30, 2020, and before November 30 of every even-numbered year
58 thereafter, the council shall report to the Health and Human Services Interim Committee on:

59 (a) the activities of the council; and

60 (b) recommendations and best practices regarding the ongoing needs of individuals in
61 the state with a rare disease.

62 Section 2. Section **63I-1-226** is amended to read:

63 **63I-1-226. Repeal dates, Title 26.**

64 (1) Section 26-1-40 is repealed July 1, 2019.

65 (2) Section 26-1-41 is repealed July 1, 2025.

66 ~~[(2)]~~ (3) Title 26, Chapter 9f, Utah Digital Health Service Commission Act, is repealed
67 July 1, 2025.

68 ~~[(3)]~~ (4) Section 26-10-11 is repealed July 1, 2020.

69 ~~[(4)]~~ (5) Subsection 26-18-417(3) is repealed July 1, 2020.

70 ~~[(5)]~~ (6) Title 26, Chapter 33a, Utah Health Data Authority Act, is repealed July 1,
71 2024.

72 ~~[(6)]~~ (7) Title 26, Chapter 36b, Inpatient Hospital Assessment Act, is repealed July 1,
73 2024.

74 ~~[(7)]~~ (8) Title 26, Chapter 36c, Medicaid Expansion Hospital Assessment Act, is
75 repealed July 1, 2024.

76 ~~[(8)]~~ (9) Title 26, Chapter 36d, Hospital Provider Assessment Act, is repealed July 1,
77 2019.

78 ~~[(9) Title 26, Chapter 56, Hemp Extract Registration Act, is repealed January 1, 2019.]~~

79 (10) Title 26, Chapter 63, Nurse Home Visiting Pay-for-Success Program, is repealed
80 July 1, 2026.