

RARE DISEASE ADVISORY COUNCIL

2020 GENERAL SESSION

STATE OF UTAH

Chief Sponsor: Lee B. Perry

Senate Sponsor: _____

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 2019, Chapters 67, 136, 246, 289, 455 and
last amended by Coordination Clause, Laws of Utah 2019, Chapter 246

ENACTS:

26-1-41, Utah Code Annotated 1953

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



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

29 **26-1-41. Rare Disease Advisory Council -- Creation -- Purpose and duties.**

30 (1) As used in this section:

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

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

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

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

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

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

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

43 (4) The council shall:

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

45 (b) be composed of:

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

47 (ii) at least the following individuals:

48 (A) a representative from the department;

49 (B) researchers and physicians who specialize in rare diseases, including at least one
50 representative from the University of Utah;

51 (C) two individuals who have a rare disease or are the parent or caregiver of an
52 individual with a rare disease; and

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

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

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

59 (6) Before November 30, 2021, and before November 30 of every odd-numbered year
60 thereafter, the council shall report to the Health and Human Services Interim Committee on:

61 (a) the activities of the council; and

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

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

65 **63I-1-226. Repeal dates, Title 26.**

66 (1) Section **26-1-40** is repealed July 1, 2022.

67 (2) Section 26-1-41 is repealed July 1, 2026.

68 ~~[(2)]~~ (3) Title 26, Chapter 9f, Utah Digital Health Service Commission Act, is repealed
69 July 1, 2025.

70 ~~[(3)]~~ (4) Section **26-10-11** is repealed July 1, 2020.

71 ~~[(4)]~~ (5) Subsection **26-18-417(3)** is repealed July 1, 2020.

72 ~~[(5)]~~ (6) Subsection **26-18-418(2)**, the language that states "and the Mental Health
73 Crisis Line Commission created in Section **63C-18-202**" is repealed July 1, 2023.

74 ~~[(6) Section 26-18-419.1 is repealed December 31, 2019.]~~

75 (7) Title 26, Chapter 33a, Utah Health Data Authority Act, is repealed July 1, 2024.

76 (8) Title 26, Chapter 36b, Inpatient Hospital Assessment Act, is repealed July 1, 2024.

77 (9) Title 26, Chapter 36c, Medicaid Expansion Hospital Assessment Act, is repealed
78 July 1, 2024.

79 (10) Title 26, Chapter 36d, Hospital Provider Assessment Act, is repealed July 1, 2024.

80 (11) Title 26, Chapter 54, Spinal Cord and Brain Injury Rehabilitation Fund and
81 Pediatric Neuro-Rehabilitation Fund, is repealed January 1, 2023.

82 (12) Subsection **26-61a-108(2)(e)(i)**, related to the Native American Legislative
83 Liaison Committee, is repealed July 1, 2022.

84 (13) Title 26, Chapter 63, Nurse Home Visiting Pay-for-Success Program, is repealed
85 July 1, 2026.