

Representative Lee B. Perry proposes the following substitute bill:

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 a grant to convene a Rare Disease Advisory Council;
- ▶ describes the composition and duties of the council; and
- ▶ establishes a review and sunset date for the grant.

Money Appropriated in this Bill:

This bill appropriates in fiscal year 2021:

- ▶ to the Department of Health - Disease Control and Prevention, as an ongoing appropriation:
 - from the General Fund, \$9,000.

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



26 last amended by Coordination Clause, Laws of Utah 2019, Chapter 246

27 ENACTS:

28 **26-1-41**, Utah Code Annotated 1953

29

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

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

32 **26-1-41. Rare Disease Advisory Council Grant Program -- Creation -- Reporting.**

33 (1) As used in this section:

34 (a) "Council" means the Rare Disease Advisory Council described in Subsection (3).

35 (b) "Grantee" means the recipient of a grant under this section to operate the program.

36 (c) "Rare disease" means a disease that affects fewer than 200,000 individuals in the
37 United States.

38 (2) (a) Within legislative appropriations, the department shall issue a request for
39 proposals for a grant to administer the provisions of this section.

40 (b) The department may issue a grant under this section if the grantee agrees to:

41 (i) convene the council in accordance with Subsection (3);

42 (ii) provide staff and other administrative support to the council; and

43 (iii) in coordination with the department, report to the Legislature in accordance with
44 Subsection (4).

45 (3) The Rare Disease Advisory Council convened by the grantee shall:

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

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

50 (c) identify best practices to improve the care and treatment of individuals in the state
51 with a rare disease;

52 (d) meet at least two times in each calendar year; and

53 (e) be composed of at least the following individuals:

54 (i) a representative from the department;

55 (ii) researchers and physicians who specialize in rare diseases, including at least one
56 representative from the University of Utah;

57 (iii) two individuals who have a rare disease or are the parent or caregiver of an
 58 individual with a rare disease; and

59 (iv) two representatives from one or more rare disease patient organizations that
 60 operate in the state.

61 (4) Before November 30, 2021, and before November 30 of every odd-numbered year
 62 thereafter, the grantee, in coordination with the council and the department, shall report to the
 63 Health and Human Services Interim Committee on:

64 (a) the activities of the grantee; and

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

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

68 **63I-1-226. Repeal dates, Title 26.**

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

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

71 ~~[(2)]~~ (3) Title 26, Chapter 9f, Utah Digital Health Service Commission Act, is repealed
 72 July 1, 2025.

73 ~~[(3)]~~ (4) Section **26-10-11** is repealed July 1, 2020.

74 ~~[(4)]~~ (5) Subsection **26-18-417(3)** is repealed July 1, 2020.

75 ~~[(5)]~~ (6) Subsection **26-18-418(2)**, the language that states "and the Mental Health
 76 Crisis Line Commission created in Section **63C-18-202**" is repealed July 1, 2023.

77 ~~[(6) Section **26-18-419.1** is repealed December 31, 2019:]~~

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

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

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

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

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

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

87 (13) Title 26, Chapter 63, Nurse Home Visiting Pay-for-Success Program, is repealed

88 July 1, 2026.

89 Section 3. **Appropriation.**

90 The following sums of money are appropriated for the fiscal year beginning July 1,
91 2020, and ending June 30, 2021. These are additions to amounts previously appropriated for
92 fiscal year 2021. Under the terms and conditions of Title 63J, Chapter 1, Budgetary Procedures
93 Act, the Legislature appropriates the following sums of money from the funds or accounts
94 indicated for the use and support of the government of the state of Utah.

95 ITEM 1

96 To Department of Health - Disease Control and Prevention

97 From General Fund, Ongoing \$9,000

98 Schedule of Programs:

99 Rare Disease Advisory Council Grant Program \$9,000

100 The Legislature intends that the appropriations provided under this item be used to fund
101 the Rare Disease Advisory Council Grant Program created in Section [26-1-41](#).