

**RARE DISEASE ADVISORY COUNCIL**

2020 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 a grant to convene a Rare Disease Advisory Council;
- ▶ describes the composition and duties of the council;
- ▶ establishes a review and sunset date for the grant; and
- ▶ provides an appropriation.

**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, \$9,500.

**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:

29 26-1-41, Utah Code Annotated 1953



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

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

33 **26-1-41. Rare Disease Advisory Council Grant Program -- Creation -- Reporting.**

34 (1) As used in this section:

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

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

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

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

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

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

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

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

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

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

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

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

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

54 (e) be composed of members identified by the department, including at least the  
55 following individuals:

- 56 (i) a representative from the department;
- 57 (ii) researchers and physicians who specialize in rare diseases, including at least one
- 58 representative from the University of Utah;
- 59 (iii) two individuals who have a rare disease or are the parent or caregiver of an
- 60 individual with a rare disease; and
- 61 (iv) two representatives from one or more rare disease patient organizations that
- 62 operate in the state.

63 (4) Before November 30, 2021, and before November 30 of every odd-numbered year  
64 thereafter, the department shall report to the Health and Human Services Interim Committee  
65 on:

- 66 (a) the activities of the grantee and the council; and
- 67 (b) recommendations and best practices regarding the ongoing needs of individuals in
- 68 the state with a rare disease.

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

70 **63I-1-226. Repeal dates, Title 26.**

- 71 (1) Section 26-1-40 is repealed July 1, 2022.
- 72 (2) Section 26-1-41 is repealed July 1, 2026.
- 73 ~~[(2)]~~ (3) Title 26, Chapter 9f, Utah Digital Health Service Commission Act, is repealed
- 74 July 1, 2025.
- 75 ~~[(3)]~~ (4) Section 26-10-11 is repealed July 1, 2020.
- 76 ~~[(4)]~~ (5) Subsection 26-18-417(3) is repealed July 1, 2020.
- 77 ~~[(5)]~~ (6) Subsection 26-18-418(2), the language that states "and the Mental Health
- 78 Crisis Line Commission created in Section 63C-18-202" is repealed July 1, 2023.
- 79 ~~[(6) Section 26-18-419.1 is repealed December 31, 2019.]~~
- 80 (7) Title 26, Chapter 33a, Utah Health Data Authority Act, is repealed July 1, 2024.
- 81 (8) Title 26, Chapter 36b, Inpatient Hospital Assessment Act, is repealed July 1, 2024.
- 82 (9) Title 26, Chapter 36c, Medicaid Expansion Hospital Assessment Act, is repealed

83 July 1, 2024.

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

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

87 (12) Subsection [26-61a-108\(2\)\(e\)\(i\)](#), related to the Native American Legislative  
88 Liaison Committee, is repealed July 1, 2022.

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

91 **Section 3. Appropriation.**

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

97 ITEM 1

98 To Department of Health - Disease Control and Prevention

99 From General Fund, Ongoing \$9,500

100 Schedule of Programs:

101 Rare Disease Advisory Council Grant Program \$9,500

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