

HB0106S01 compared with HB0106

~~text~~ shows text that was in HB0106 but was deleted in HB0106S01.

text shows text that was not in HB0106 but was inserted into HB0106S01.

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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 ~~the~~ a grant to convene a 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~~ grant.

Money Appropriated in this Bill:

~~None~~ This bill appropriates in fiscal year 2021:

- ▶ to the Department of Health - Disease Control and Prevention, as an ongoing

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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 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:

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

26-1-41. Rare Disease Advisory Council Grant Program -- Creation -- ~~{Purpose and duties}~~Reporting.

(1) As used in this section:

(a) "Council" means the Rare Disease Advisory Council ~~{created}~~described in

Subsection (3).

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

~~{b}~~c "Rare disease" means a disease that affects fewer than 200,000 individuals in the United States.

(2) ~~{There is created within the department.}~~(a) Within legislative appropriations, the department shall issue a request for proposals for a grant to administer the provisions of this section.

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

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

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

(iii) in coordination with the ~~{University of Utah, the}~~department, report to the

Legislature in accordance with Subsection (4).

(3) The Rare Disease Advisory Council~~{~~

~~— (3) The purpose of~~ convened by the ~~{council is to}~~grantee shall:

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

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

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

~~{ (4) The council shall:~~

~~{ (a) d) meet at least two times in each calendar year; and~~

~~(b) e) be composed of:~~

~~— (i) members appointed by the executive director; and~~

~~— (ii) } at least the following individuals:~~

~~(A) i) a representative from the department;~~

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

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

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

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

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

~~{ (6) 4) Before November 30, 2021, and before November 30 of every odd-numbered year thereafter, the grantee, in coordination with the council and the department, shall report to the Health and Human Services Interim Committee on:~~

~~(a) the activities of the ~~{council}~~ grantee; and~~

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Section 3. Appropriation.

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

ITEM 1

To Department of Health - Disease Control and Prevention

From General Fund, Ongoing \$9,000

Schedule of Programs:

Rare Disease Advisory Council Grant Program \$9,000

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