

# HB0211S01 compared with HB0211

~~text~~ shows text that was in HB0211 but was deleted in HB0211S01.

Inserted text shows text that was not in HB0211 but was inserted into HB0211S01.

**DISCLAIMER:** This document is provided to assist you in your comparison of the two bills. Sometimes this automated comparison will NOT be completely accurate. Therefore, you need to read the actual bills. This automatically generated document could contain inaccuracies caused by: limitations of the compare program; bad input data; or other causes.

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: \_\_\_\_\_

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### 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;~~and~~
- ▶ 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

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### Utah Code Sections Affected:

#### AMENDS:

631-1-226, as last amended by Laws of Utah 2018, Third Special Session, Chapter 1

#### ENACTS:

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

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*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 -- Creation -- Purpose and duties.**

(1) As used in this section:

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

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

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

(3) The purpose of the council is to:

(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;†

~~(c) coordinate with other organizations within the state that focus on rare diseases, including medical schools, schools of public health, and hospitals, to encourage greater cooperation regarding the research, diagnosis, and treatment of rare diseases;‡~~ and

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

(4) The council shall:

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

(b) be composed of:

(i) members appointed by the executive director; and

(ii) at least the following individuals:

(A) a representative from the department;

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(B) researchers and health care practitioners who specialize in rare diseases;

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

and

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

(a) the activities of the council; 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.

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

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

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

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

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

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

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

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