

RARE DISEASE ADVISORY COUNCIL

2019 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 the Rare Disease Advisory Council within the Department of Health; and
- ▶ describes the composition and duties of the council.

Money Appropriated in this Bill:

None

Other Special Clauses:

None

Utah Code Sections Affected:

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 -- Creation -- Purpose and duties.

(1) As used in this section:

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



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

30 (2) There is created within the department the Rare Disease Advisory Council.

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

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

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

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

39 (d) identify best practices to improve the care and treatment of individuals in the state
40 with a rare disease.

41 (4) The council shall:

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

43 (b) be composed of:

44 (i) members appointed by the director; and

45 (ii) at least the following individuals:

46 (A) a representative from the department;

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

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

49 and

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

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

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

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

58 (a) the activities of the council; and

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