

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

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

28 **26-1-41. Rare Disease Advisory Council -- Creation -- Purpose and duties.**

29 (1) As used in this section:

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

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

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

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

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

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

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

42 (4) The council shall:

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

44 (b) be composed of:

45 (i) members appointed by the executive director; and

46 (ii) at least the following individuals:

47 (A) a representative from the department;

48 (B) researchers and ~~H→~~ [health care practitioners] physicians ~~←H~~ who specialize in rare  
48a diseases ~~H→~~ , including at least one representative from the University of Utah ~~←H~~ ;

49 (C) two individuals who are the ~~H→~~ patient, ~~←H~~ parent ~~H→~~ , ~~←H~~ or caregiver of an  
49a individual with a rare disease;

50 and

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

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

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