



House of Representatives *State of Utah*

UTAH STATE CAPITOL COMPLEX • 350 STATE CAPITOL
P.O. BOX 145030 • SALT LAKE CITY, UTAH 84114-5030 • (801) 538-1029

February 11, 2019

Mr. Speaker,

The Health and Human Services Committee recommends **H.B. 211**, RARE DISEASE ADVISORY COUNCIL, by Representative L. B. Perry, be replaced and reports a favorable recommendation on **1st Sub. H.B. 211**, RARE DISEASE ADVISORY COUNCIL with the following amendments:

1. *Page 2, Lines 46 through 51:*

- 46 (ii) at least the following individuals:
- 47 (A) a representative from the department;
- 48 (B) researchers and {~~health care practitioners~~} physicians who
specialize in rare diseases , including at least one representative from the University
of Utah ;
- 49 (C) two individuals who are the patient, parent , or caregiver of an
individual with a rare disease;
- 50 and
- 51 (D) two representatives from rare disease patient organizations that operate in the
state.

Respectfully,

Brad M. Daw
Chair

Voting: 10-0-2

5 HB0211.HC2.wpd 2/11/19 5:3 pm sfigueroa/KR DC/MDA

Bill Number



HB0211S01

Action Class



H

Action Code



HCRSUBAMD