



MINUTES

HOUSE HEALTH AND HUMAN SERVICES STANDING COMMITTEE

LEGISLATURE

Monday, February 11, 2019 | 3:40 p.m. | 210 Senate Building

Members Present:

Rep. Brad M. Daw, Chair
Rep. Kelly B. Miles, Vice Chair
Rep. Stewart E. Barlow
Rep. Jennifer Dailey-Provost
Rep. Steve Eliason
Rep. Sandra Hollins
Rep. Marsha Judkins
Rep. Paul Ray

Rep. Rex P. Shipp
Rep. Norman K. Thurston
Rep. Raymond P. Ward

Members Absent:

Rep. Robert M. Spendlove

Staff Present:

Ms. Karin M. Rueff, Policy Analyst
Ms. Karen C. Allred, Committee Secretary

Note: A copy of related materials and an audio recording of the meeting can be found at www.le.utah.gov.

Motion passed. passed with a vote of 10 - 0 - 2.

Yeas-10

Rep. S. Barlow
Rep. J. Dailey-Provost
Rep. B. Daw
Rep. S. Eliason
Rep. S. Hollins
Rep. M. Judkins
Rep. K. Miles
Rep. P. Ray
Rep. R. Shipp
Rep. R. Ward

Nays-0

Absent-2

Rep. R. Spendlove
Rep. N. Thurston

Chair Daw called the meeting to order at 3:46 p.m.

MOTION:

Rep. Miles moved to approve the minutes of the February 6, 2019 meeting. The motion passed with a vote of 8 - 0 - 4.

Yeas-8

Rep. S. Barlow
Rep. B. Daw
Rep. S. Hollins
Rep. M. Judkins
Rep. K. Miles
Rep. P. Ray
Rep. R. Shipp
Rep. N. Thurston

Nays-0

Absent-4

Rep. J. Dailey-Provost
Rep. S. Eliason
Rep. R. Spendlove
Rep. R. Ward

1 . H.B. 211 Rare Disease Advisory Council (Perry, L.)

Rep. Lee B. Perry presented the bill with the assistance of Ms. Gina Szajnuik, Co-Founder, Rare and Undiagnosed Network, and Ava Szajnuik.

Ms. Justine Case, Co-Ambassador, Rare Action Network, spoke in favor of the bill.

MOTION: Rep. Ray moved to replace H.B. 211 with 1st Substitute H.B. 211. The motion passed with a vote of 9 - 0 - 3.

Yeas-9

Rep. S. Barlow
Rep. J. Dailey-Provost
Rep. B. Daw
Rep. S. Eliason
Rep. S. Hollins
Rep. M. Judkins
Rep. K. Miles
Rep. P. Ray
Rep. R. Shipp

Nays-0

Absent-3

Rep. R. Spendlove
Rep. N. Thurston
Rep. R. Ward

MOTION: Rep. Barlow moved to amend 1st Substitute H.B. 211 with Amendment #1. The motion passed with a vote of 10 - 0 - 2.

Amendment 1
1st Sub. H.B. 211

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 } physicans 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.

Yeas-10

Rep. S. Barlow
Rep. J. Dailey-Provost
Rep. B. Daw
Rep. S. Eliason
Rep. S. Hollins
Rep. M. Judkins
Rep. K. Miles
Rep. P. Ray
Rep. R. Shipp
Rep. R. Ward

Nays-0

Absent-2

Rep. R. Spendlove
Rep. N. Thurston

MOTION: Rep. Ray moved to pass 1st Substitute H.B. 211 out favorably. The motion passed with a vote of 10 - 0 - 2.

Yeas-10

Rep. S. Barlow
Rep. J. Dailey-Provost
Rep. B. Daw
Rep. S. Eliason
Rep. S. Hollins
Rep. M. Judkins
Rep. K. Miles
Rep. P. Ray
Rep. R. Shipp
Rep. R. Ward

Nays-0

Absent-2

Rep. R. Spendlove
Rep. N. Thurston

2 . H.B. 261 Office of Quality and Design (Hawkins, J.)

Rep. Jon Hawkins presented the bill with the assistance of Mr. Justin Naylor, Director, Office of Quality and Design.



MOTION: Rep. Ray moved to pass H.B. 261 out favorably. The motion passed with a vote of 8 - 0 - 4.

Yeas-8

- Rep. J. Dailey-Provost
- Rep. B. Daw
- Rep. S. Eliason
- Rep. M. Judkins
- Rep. K. Miles
- Rep. P. Ray
- Rep. R. Shipp
- Rep. R. Ward

Nays-0

Absent-4

- Rep. S. Barlow
- Rep. S. Hollins
- Rep. R. Spendlove
- Rep. N. Thurston

MOTION: Rep. Ray moved to adjourn. The motion passed with a vote of 8 - 0 - 4.

Yeas-8

- Rep. J. Dailey-Provost
- Rep. B. Daw
- Rep. S. Eliason
- Rep. M. Judkins
- Rep. K. Miles
- Rep. P. Ray
- Rep. R. Shipp
- Rep. R. Ward

Nays-0

Absent-4

- Rep. S. Barlow
- Rep. S. Hollins
- Rep. R. Spendlove
- Rep. N. Thurston

Chair Daw adjourned the meeting at 4:34 p.m.