

SENATE COMMITTEE OF REFERENCE AMENDMENT

Committee on Health & Human Services.

SB22-186 be amended as follows:

1 Amend printed bill, page 3, line 25, strike "PERSONS" and substitute
2 "PEOPLE".

3 Page 5, strike lines 2 through 27 and substitute:

4 "I) THE PRESIDENT OF THE SENATE SHALL APPOINT THREE
5 MEMBERS, INCLUDING:

6 (A) ONE REPRESENTATIVE FROM ACADEMIC RESEARCH IN THE
7 STATE WHO RECEIVES GRANT FUNDING FOR RARE DISEASE RESEARCH;

8 (B) ONE GENETICIST PRACTICING IN COLORADO; AND

9 (C) ONE PHYSICIAN LICENSED AND PRACTICING IN COLORADO
10 WITH EXPERIENCE TREATING RARE DISEASES;

11 (II) THE MINORITY LEADER OF THE SENATE SHALL APPOINT THREE
12 MEMBERS, INCLUDING:

13 (A) ONE REGISTERED NURSE OR ADVANCED PRACTICE REGISTERED
14 NURSE LICENSED AND PRACTICING IN COLORADO WITH EXPERIENCE
15 TREATING RARE DISEASES;

16 (B) ONE PHARMACIST WITH EXPERIENCE DISPENSING DRUGS USED
17 TO TREAT RARE DISEASES; AND

18 (C) ONE PERSON WHO HAS A RARE DISEASE;

19 (III) THE SPEAKER OF THE HOUSE OF REPRESENTATIVES SHALL
20 APPOINT THREE MEMBERS, INCLUDING:

21 (A) ONE REPRESENTATIVE OF A RARE DISEASE PATIENT
22 ORGANIZATION OPERATING IN COLORADO THAT IS NOT AFFILIATED WITH
23 THE FACILITATOR;

24 (B) ONE REPRESENTATIVE OF THE BIOTECHNOLOGY OR
25 PHARMACEUTICAL INDUSTRY; AND

26 (C) ONE REPRESENTATIVE OF A HEALTH INSURER; AND

27 (IV) THE MINORITY LEADER OF THE HOUSE OF REPRESENTATIVES
28 SHALL APPOINT THREE MEMBERS, INCLUDING:

29 (A) ONE PERSON WHO HAS A RARE DISEASE;

30 (B) ONE PARENT WHOSE CHILD OR CHILDREN HAVE BEEN
31 DIAGNOSED WITH A RARE DISEASE; AND

32 (C) ONE CAREGIVER OF A PERSON WITH A RARE DISEASE.".

33 Page 6, strike line 1.

34 Page 6, line 17, strike "BOARD" and substitute "COUNCIL".

35 Page 7, line 3, strike "**powers.**" and substitute "**duties.**".

- 1 Page 7, line 6, strike "HEARINGS," and substitute "MEETINGS,".
- 2 Page 7, strike lines 21 through 23.
- 3 Reletter succeeding paragraphs accordingly.
- 4 Page 8, line 6, strike "REPORT" and substitute "PREPARE AND SUBMIT A REPORT".
- 6 Page 8, strike lines 12 and 13 and substitute:
 - 7 "(3) IN ADDITION TO ANY OTHER COUNCIL ACTIVITIES, THE COUNCIL MAY:".
- 9 Page 8, line 26, strike "**funding.**" and substitute "**fiscal agent.**".
- 10 Page 10, strike line 23.
- 11 Page 10, line 24, strike "SECTION, THE" and substitute:
 - 12 "(4) THE".
- 13 Page 10, strike line 27.
- 14 Page 11, strike lines 1 through 5.
- 15 Page 11, line 13, strike "COMMITTEES" and substitute "COMMITTEE".
- 16 Page 11, line 27, after "(2)" insert "(a)".
- 17 Page 12, after line 2 insert:
 - 18 "(b) NOTWITHSTANDING SECTION 24-1-136 (11)(a)(I), THE REPORTING REQUIREMENTS SET FORTH IN SUBSECTION (2)(a) OF THIS SECTION CONTINUE UNTIL THE REPEAL OF THIS PART 15 PURSUANT TO SECTION 25-1-1511.".
- 22 Page 12, lines 8 and 9, strike "COUNCIL FACILITATOR." and substitute "FACILITATOR.".
- 24 Page 12, line 10, strike "COUNCIL FACILITATOR" and substitute "FACILITATOR".

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