

SENATE COMMITTEE OF REFERENCE REPORT

_____ Date April 18, 2022
Chair of Committee

Committee on Health & Human Services.

After consideration on the merits, the Committee recommends the following:

SB22-186 be amended as follows, and as so amended, be referred to the Committee on Appropriations with favorable recommendation:

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

1 (IV) THE MINORITY LEADER OF THE HOUSE OF REPRESENTATIVES
2 SHALL APPOINT THREE MEMBERS, INCLUDING:
3 (A) ONE PERSON WHO HAS A RARE DISEASE;
4 (B) ONE PARENT WHOSE CHILD OR CHILDREN HAVE BEEN
5 DIAGNOSED WITH A RARE DISEASE; AND
6 (C) ONE CAREGIVER OF A PERSON WITH A RARE DISEASE."

7 Page 6, strike line 1.

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

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

10 Page 7, line 6, strike "HEARINGS," and substitute "MEETINGS,".

11 Page 7, strike lines 21 through 23.

12 Reletter succeeding paragraphs accordingly.

13 Page 8, line 6, strike "REPORT" and substitute "PREPARE AND SUBMIT A
14 REPORT".

15 Page 8, strike lines 12 and 13 and substitute:

16 "(3) IN ADDITION TO ANY OTHER COUNCIL ACTIVITIES, THE
17 COUNCIL MAY:".

18 Page 8, line 26, strike "**funding.**" and substitute "**fiscal agent.**".

19 Page 10, strike line 23.

20 Page 10, line 24, strike "SECTION, THE" and substitute:

21 "(4) THE".

22 Page 10, strike line 27.

23 Page 11, strike lines 1 through 5.

24 Page 11, line 13, strike "COMMITTEES" and substitute "COMMITTEE".

25 Page 11, line 27, after "(2)" insert "(a)".

26 Page 12, after line 2 insert:

1 "(b) NOTWITHSTANDING SECTION 24-1-136 (11)(a)(I), THE
2 REPORTING REQUIREMENTS SET FORTH IN SUBSECTION (2)(a) OF THIS
3 SECTION CONTINUE UNTIL THE REPEAL OF THIS PART 15 PURSUANT TO
4 SECTION 25-1-1511."

5 Page 12, lines 8 and 9, strike "COUNCIL FACILITATOR." and substitute
6 "FACILITATOR."

7 Page 12, line 10, strike "COUNCIL FACILITATOR" and substitute
8 "FACILITATOR".

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