



General Assembly

Amendment

January Session, 2015

LCO No. 7536



Offered by:
REP. RITTER M., 1st Dist.

To: Subst. House Bill No. 6580 File No. 465 Cal. No. 294

"AN ACT CREATING AN ADVISORY COUNCIL ON RARE DISEASES."

1 Strike everything after the enacting clause and substitute the
2 following in lieu thereof:

3 "Section 1. (*Effective from passage*) (a) There is established a task force
4 to study rare diseases. The task force shall (1) examine research,
5 diagnoses, treatment and education relating to rare diseases, and (2)
6 make recommendations for the establishment of a permanent group of
7 experts to advise the Department of Public Health on rare diseases. For
8 purposes of this section, "rare disease" has the same meaning as
9 provided in 21 USC 360bb, as amended from time to time.

10 (b) The task force shall consist of the following members:

11 (1) Four appointed by the speaker of the House of Representatives,
12 one of whom shall be a physician licensed and practicing in the state
13 with experience researching, diagnosing or treating rare diseases and
14 representing the specialty of neurology or neurological surgery, one of

15 whom shall be a physician licensed and practicing in the state with
16 experience researching, diagnosing or treating rare diseases and
17 representing the specialty of pediatrics, one of whom shall be an
18 administrator of a hospital in the state, and one of whom shall be a
19 medical researcher with experience conducting research concerning
20 rare diseases;

21 (2) Four appointed by the president pro tempore of the Senate, one
22 of whom shall be a physician licensed and practicing in the state with
23 experience researching, diagnosing or treating rare diseases and
24 representing the specialty of cardiology or cardiovascular surgery, one
25 of whom shall be a physician licensed and practicing in the state with
26 experience researching, diagnosing or treating rare diseases and
27 representing the specialty of pulmonology, one of whom shall be a
28 representative of a hospital in the state, and one of whom shall be a
29 registered nurse or advanced practice registered nurse licensed and
30 practicing in the state with experience treating rare diseases;

31 (3) Two appointed by the majority leader of the House of
32 Representatives, one of whom shall be a physician licensed and
33 practicing in the state with experience researching, diagnosing or
34 treating rare diseases and representing the specialty of orthopedics or
35 orthopedic surgery, and one of whom shall be a rare disease survivor
36 over the age of eighteen;

37 (4) Two appointed by the majority leader of the Senate, one of
38 whom shall be a physician licensed and practicing in the state with
39 experience researching, diagnosing or treating rare diseases and
40 representing the specialty of internal medicine, and one of whom shall
41 be a caregiver of a pediatric rare disease survivor;

42 (5) Two appointed by the minority leader of the House of
43 Representatives, one of whom shall be a physician licensed and
44 practicing in the state with experience researching, diagnosing or
45 treating rare diseases and representing the specialty of emergency
46 medicine, and one of whom shall be a representative of the National

47 Organization for Rare Disorders;

48 (6) Two appointed by the minority leader of the Senate, one of
49 whom shall be a representative of the biopharmaceutical industry in
50 the state with experience in research and development relating to rare
51 diseases, and one of whom shall be a representative of a hospital in the
52 state with experience in research and development relating to rare
53 diseases; and

54 (7) The Commissioner of Public Health, or the commissioner's
55 designee.

56 (c) Any member of the task force appointed under subdivision (1),
57 (2), (3), (4), (5) or (6) of subsection (b) of this section may be a member
58 of the General Assembly.

59 (d) All appointments to the task force shall be made not later than
60 thirty days after the effective date of this section. Any vacancy shall be
61 filled by the appointing authority.

62 (e) The speaker of the House of Representatives and the president
63 pro tempore of the Senate shall select the chairpersons of the task force
64 from among the members of the task force. Such chairpersons shall
65 schedule the first meeting of the task force, which shall be held not
66 later than sixty days after the effective date of this section.

67 (f) The administrative staff of the joint standing committee of the
68 General Assembly having cognizance of matters relating to public
69 health shall serve as administrative staff of the task force.

70 (g) Not later than January 1, 2016, the task force shall submit a
71 report on its findings and recommendations to the joint standing
72 committee of the General Assembly having cognizance of matters
73 relating to public health, in accordance with the provisions of section
74 11-4a of the general statutes. The task force shall terminate on the date
75 that it submits such report or January 1, 2016, whichever is later."

This act shall take effect as follows and shall amend the following sections:		
Section 1	<i>from passage</i>	New section