

SECOND REGULAR SESSION

[PERFECTED]

HOUSE COMMITTEE SUBSTITUTE FOR

HOUSE BILL NO. 2740

103RD GENERAL ASSEMBLY

4420H.03P

JOSEPH ENGLER, Chief Clerk

AN ACT

To amend chapter 173, RSMo, by adding thereto one new section relating to the pediatric disease task force.

Be it enacted by the General Assembly of the state of Missouri, as follows:

Section A. Chapter 173, RSMo, is amended by adding thereto one new section, to be
2 known as section 173.690, to read as follows:

173.690. 1. As used in this section, the following terms mean:

2 (1) "Genetic disease", any disease, disorder, or condition caused in whole or in
3 part by genetic variation, mutation, or inherited genetic traits;

4 (2) "Pediatric disease", any disease, disorder, or condition that primarily affects
5 individuals under eighteen years of age;

6 (3) "Rare pediatric disease", a life-threatening or chronically debilitating disease
7 that affects fewer than two hundred thousand individuals under eighteen years of age in
8 the United States.

9 2. There is hereby established within the department of higher education and
10 workforce development the "Pediatric Disease Task Force".

11 3. The task force shall consist of the following members:

12 (1) The director of the department of higher education and workforce
13 development or his or her designee;

14 (2) The director of the department of health and senior services or his or her
15 designee;

16 (3) Four members shall be from the general assembly composed of the following:

EXPLANATION — Matter enclosed in bold-faced brackets ~~thus~~ in the above bill is not enacted and is intended to be omitted from the law. Matter in **bold-face** type in the above bill is proposed language.

17 **(a) The president pro tempore of the senate shall appoint two members of the**
18 **senate of whom not more than one shall be of the same party; and**

19 **(b) The speaker of the house of representatives shall appoint two members of the**
20 **house of representatives of whom not more than one shall be of the same party; and**

21 **(c) The legislative members shall serve on the task force until such time as they**
22 **resign, are no longer members of the general assembly, or are replaced by new**
23 **appointments; and**

24 **(4) Eight members to be appointed by the governor with the advice and consent**
25 **of the senate, composed of the following:**

26 **(a) Two members who represent public universities and who have expertise in**
27 **pediatric diseases, with at least one member who represents the University of Missouri;**

28 **(b) Two members who represent the private health care research industry and**
29 **who have expertise in pediatric diseases;**

30 **(c) Two members who represent the private research industry and who have**
31 **expertise in pediatric diseases;**

32 **(d) One member representing a collaborating nonprofit or industry partner; and**

33 **(e) One member representing a patient advocacy group.**

34 **4. Beginning January 1, 2027, the task force shall meet at least quarterly. The**
35 **department of higher education and workforce development shall provide necessary**
36 **clerical support and assistance in order to facilitate meetings of the task force.**

37 **5. The task force shall submit an annual public report to the governor and the**
38 **general assembly no later than December thirty-first of each year detailing:**

39 **(1) Research initiatives focused on genetic or pediatric diseases, including rare**
40 **pediatric diseases, led by institutions located in this state;**

41 **(2) Key outcomes achieved by the research initiatives;**

42 **(3) Funds expended and leveraged by the research initiatives; and**

43 **(4) Any legislative recommendations.**

44 **6. This section shall expire on December 31, 2030.**

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