

SECOND REGULAR SESSION  
HOUSE COMMITTEE SUBSTITUTE FOR  
**HOUSE BILL NO. 2740**  
**103RD GENERAL ASSEMBLY**

4420H.03C

JOSEPH ENGLER, Chief Clerk

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**AN ACT**

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

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*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:

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

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.

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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