



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

Be it enacted by the Senate and House of Representatives in General Assembly convened:

1 Section 1. (NEW) (*Effective July 1, 2015*) (a) There is established an  
2 advisory council on rare diseases to advise the Commissioner of Public  
3 Health on research, diagnosis, treatment and education relating to rare  
4 diseases. For purposes of this section, "rare disease" has the same  
5 meaning as provided in 21 USC 360bb, as amended from time to time.

6 (b) The advisory council shall consist of the following members,  
7 who shall be appointed by the Commissioner of Public Health:

8 (1) Five physicians licensed and practicing in the state with  
9 experience researching, diagnosing or treating rare diseases and  
10 representing each of the following specialties:

11 (A) Neurology or neurological surgery;

12 (B) Cardiology or cardiovascular surgery;

13 (C) Orthopedics or orthopedic surgery;

14 (D) Internal medicine; and

15 (E) Emergency medicine;

16 (2) A medical researcher with experience conducting research

17 concerning rare diseases;

18 (3) A registered nurse or advanced practice registered nurse  
19 licensed and practicing in the state with experience treating rare  
20 diseases;

21 (4) One hospital administrator from each hospital in the state that  
22 provides care to persons diagnosed with a rare disease, or such  
23 administrator's designee;

24 (5) One rare disease survivor over the age of eighteen;

25 (6) One caregiver of a pediatric rare disease survivor; and

26 (7) A representative of the National Organization for Rare  
27 Disorders.

28 (c) The chairpersons of the joint standing committee of the General  
29 Assembly having cognizance of matters relating to public health, or  
30 the chairpersons' designees, shall be members of the advisory council.

31 (d) The Commissioner of Public Health, or the commissioner's  
32 designee, shall be an ex-officio, nonvoting member of the advisory  
33 council and shall attend all meetings of the advisory council.

34 (e) Any member of the advisory council under subsection (c) of this  
35 section may be a member of the General Assembly.

36 (f) All appointments to the advisory council shall be made not later  
37 than thirty days after the effective date of this section. Members  
38 appointed pursuant to subsection (b) of this section shall serve for a  
39 term of three years and no member shall serve more than two  
40 consecutive terms.

41 (g) Members shall receive no compensation except for  
42 reimbursement for necessary expenses incurred in performing their  
43 duties.

44 (h) The Commissioner of Public Health shall schedule the first  
45 meeting of the advisory council, which shall be held not later than  
46 September 1, 2015. The members shall elect the chairperson of the  
47 advisory council from among the members of the council. A majority  
48 of the council members shall constitute a quorum. A majority vote of a  
49 quorum shall be required for any official action of the advisory  
50 council. The advisory council shall meet upon the call of the  
51 chairperson or upon the request of a majority of council members.

52 (i) Not later than January 1, 2016, and annually thereafter, the  
53 advisory council shall report, in accordance with the provisions of  
54 section 11-4a of the general statutes, to the joint standing committee of  
55 the General Assembly having cognizance of matters relating to public  
56 health. Such report shall include, but need not be limited to,  
57 recommendations concerning: (1) Practice guidelines for the diagnosis  
58 and treatment of rare diseases; (2) mechanisms to increase clinical  
59 awareness and education regarding rare diseases; (3) outreach to  
60 educators to increase awareness of rare diseases; and (4) development  
61 of a network of volunteer experts on the diagnosis and treatment of  
62 rare diseases.

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| This act shall take effect as follows and shall amend the following sections: |              |             |
| Section 1   | July 1, 2015 | New section |

**Statement of Legislative Commissioners:**

In Section 1(f), "Members shall serve for a term of three years" was changed to "Members appointed pursuant to subsection (b) of this section shall serve for a term of three years" for clarity and accuracy.

**PH** Joint Favorable Subst. -LCO