



# House of Representatives

General Assembly

**File No. 465**

January Session, 2015

Substitute House Bill No. 6580

*House of Representatives, April 7, 2015*

The Committee on Public Health reported through REP. RITTER of the 1st Dist., Chairperson of the Committee on the part of the House, that the substitute bill ought to pass.

## **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.

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

The following Fiscal Impact Statement and Bill Analysis are prepared for the benefit of the members of the General Assembly, solely for purposes of information, summarization and explanation and do not represent the intent of the General Assembly or either chamber thereof for any purpose. In general, fiscal impacts are based upon a variety of informational sources, including the analyst's professional knowledge. Whenever applicable, agency data is consulted as part of the analysis, however final products do not necessarily reflect an assessment from any specific department.

**OFA Fiscal Note**

**State Impact:**

Agency Affected	Fund-Effect	FY 16 \$	FY 17 \$
Various State Agencies	GF - Cost	Less than \$1,000	Less than \$1,000

Note: GF=General Fund

**Municipal Impact:** None

**Explanation**

There may be a cost of less than \$1,000 in FY 16 and in FY 17 to various state agencies to reimburse those participating on the council for mileage expenses.

**The Out Years**

The annualized ongoing fiscal impact identified above would continue into the future subject to inflation.

**OLR Bill Analysis****HB 6580*****AN ACT CREATING AN ADVISORY COUNCIL ON RARE DISEASES.*****SUMMARY:**

This bill establishes an advisory council on rare diseases. The council must advise the public health (DPH) commissioner on rare disease research, diagnosis, treatment, and education. It must annually report to the Public Health Committee, with the first report due by January 1, 2016.

The bill incorporates a definition of “rare disease” from federal law. Under that law, rare diseases are those that (1) affect fewer than 200,000 people in the United States or (2) affect more than that but there is no reasonable expectation that the cost to develop and make a drug for the disease available in the United States will be recovered from its domestic sales (21 USC § 360bb).

EFFECTIVE DATE: July 1, 2015

**RARE DISEASE ADVISORY COUNCIL*****Membership***

Under the bill, the DPH commissioner appoints most council members. The membership also includes the Public Health Committee chairpersons or their designees, who may also be legislators. The DPH commissioner, or her designee, is an ex-officio, nonvoting member and must attend all council meetings.

The appointed members are as follows:

1. five physicians licensed and practicing in Connecticut, with experience researching, diagnosing, or treating rare diseases,

who represent the following specialties: neurology or neurological surgery, cardiology or cardiovascular surgery, orthopedics or orthopedic surgery, internal medicine, and emergency medicine;

2. a medical researcher with experience researching rare diseases;
3. a registered nurse or advanced practice registered nurse licensed and practicing in Connecticut with experience treating these diseases;
4. a hospital administrator, or designee, from each hospital in the state that cares for patients with rare diseases;
5. a rare disease survivor over age 18;
6. a caregiver of a pediatric rare disease survivor; and
7. a representative of the National Organization for Rare Disorders.

The commissioner must make the appointments by July 31, 2015. Appointed members serve three-year terms and may serve no more than two consecutive terms.

The council must elect a chairperson from among its members.

### ***Procedure***

The DPH commissioner must schedule the first council meeting, to be held by September 1, 2015. The council must meet upon (1) the call of the chairperson or (2) a request of a majority of the members. A majority of the members constitutes a quorum, and a majority vote of a quorum is needed for official council action.

Council members are not paid for their service, except for reimbursement for necessary expenses incurred in performing their duties.

### ***Reporting Requirement***

Under the bill, the council must report by January 1, 2016 and

annually after that to the Public Health Committee. The report must include recommendations on:

1. practice guidelines for diagnosing and treating rare diseases;
2. ways to increase clinical awareness of and education about rare diseases;
3. outreach to educators to increase awareness; and
4. developing a network of volunteer experts on diagnosing and treating these diseases.

**COMMITTEE ACTION**

Public Health Committee

Joint Favorable

Yea 27 Nay 0 (03/23/2015)