

Substitute House Bill No. 7222
Public Act No. 17-146

Sec. 23. Section 35 of public act 15-242 is repealed and the following is substituted in lieu thereof (*Effective from passage*):

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

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

(1) Four appointed by the speaker of the House of Representatives, one of whom shall be a physician licensed and practicing in the state with experience researching, diagnosing or treating rare diseases and representing the specialty of neurology or neurological surgery, one of whom shall be a physician licensed and practicing in the state with experience researching, diagnosing or treating rare diseases and representing the specialty of pediatrics, one of whom shall be an administrator of a hospital in the state, and one of whom shall be a medical researcher with experience conducting research concerning rare diseases;

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

(3) Two appointed by the majority leader of the House of Representatives, one of whom shall be a physician licensed and practicing in the state with experience researching, diagnosing or treating rare diseases and representing the specialty of

orthopedics or orthopedic surgery, and one of whom shall be a rare disease survivor over the age of eighteen;

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

(5) Two appointed by the minority leader of the House of Representatives, one of whom shall be a physician licensed and practicing in the state with experience researching, diagnosing or treating rare diseases and representing the specialty of emergency medicine, and one of whom shall be a representative of the National Organization for Rare Disorders; [and]

(6) Two appointed by the minority leader of the Senate, one of whom shall be a representative of the biopharmaceutical industry in the state with experience in research and development relating to rare diseases, and one of whom shall be a representative of a hospital in the state with experience in research and development relating to rare diseases; [.] and

(7) The chairpersons of the General Assembly having cognizance of matters relating to public health, or such chairpersons' designee.

(c) Any member of the task force appointed under subdivision (1), (2), (3), (4), (5), [or] (6) or (7) of subsection (b) of this section may be a member of the General Assembly.

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

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

(f) Not later than January 1, [2016] 2018, the task force shall submit a report on its findings and recommendations to the joint standing committee of the General

Assembly having cognizance of matters relating to public health, in accordance with the provisions of section 11-4a of the general statutes. The task force shall terminate on the date that it submits such report or January 1, [2016] 2018, whichever is later.