

SENATE APPROPRIATIONS COMMITTEE FISCAL NOTE

BILL NO. House Bill 239

PRINTER NO. 2005

AMOUNT

No Adverse Fiscal Impact

FUND

General Fund

DATE INTRODUCED

June 21, 2017

PRIME SPONSOR

Representative Toepel

DESCRIPTION AND PURPOSE OF BILL

House Bill 239 enacts the Rare Disease Advisory Council Act and establishes the Rare Disease Advisory Council within the Department of Health ("Department").

Defines "rare disease" as a disease or condition that affects fewer than 200,000 individuals in the United States.

Establishes the Rare Disease Advisory Council with the following members:

- The Secretary of the Department.
- The heads of State agencies concerned with the provision of care to persons with rare diseases (at a minimum the Secretary of Human Services and the Secretary of Education).
- The Insurance Commissioner.
- Public members, including:
 - Three physicians with expertise in rare diseases;
 - Two registered nurses or nurse practitioners with expertise in rare diseases;
 - An epidemiologist with expertise in rare diseases;
 - Two representatives of hospitals (one of which is a research hospital);
 - Two representatives of the health insurance industry;
 - Two representatives of the biopharmaceutical industry;
 - Two representatives of the scientific community engaged in rare disease research;
 - Two parents of children with rare diseases;
 - Two individuals with rare diseases;
 - Representatives of two rare disease-specific patient organizations.
- Additional at-large members as recommended by the Council.

Requires the Secretary of the Department to appoint the chairperson and the public members. Public members shall serve without compensation, but may be reimbursed for related expenses within the limits of funds made available to the advisory council for its purposes.

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Requires the advisory council to meet a minimum of three times per year. The advisory council may request assistance from any State or local government agency, and may receive staff from the Department.

The purpose of the advisory council is to:

- Coordinate Statewide efforts for the study of the incidence and prevalence of rare diseases.
- Act as the advisory body on rare diseases to the General Assembly and all State and private agencies.
- Coordinate efforts with other rare disease advisory bodies for the purpose of ensuring greater cooperation with federal agencies.

The duties of the advisory council shall be to:

- Research and determine the most appropriate method to collect rare disease data in order to conduct comprehensive surveys of rare diseases.
- Ensure that its research is coordinated and interoperable with other similar research.
- Research and identify priorities.
- Identify best practices.
- Raise public awareness of rare diseases.
- Coordinate and develop a task force to facilitate the final report of the council to the General Assembly.

Requires the Department to research and report to the General Assembly existing sources of funding for the operation of the advisory council prior to appointing members to the council and within 30 days of the effective date of this section. Authorizes the advisory council to apply for federal grants, private funds and other sources of funding.

Requires the advisory council to deliver to the General Assembly a preliminary report on the work of the advisory council within 12 months. A comprehensive report shall be delivered within two years, and shall include the incidence and prevalence of rare diseases and the needs of the rare disease community.

Requires the advisory council to report biennially to the General Assembly on the activities of the advisory council and its findings and recommendations.

This act expires June 30, 2025.

This act shall take effect immediately.

FISCAL IMPACT:

House Bill 239 will have no adverse fiscal impact to the Commonwealth. The Department of Health would be required to reimburse members of the council for travel and related expenses. This reimbursement could be absorbed by Department of Health's General Government Operations appropriation.