



HOUSE COMMITTEE ON APPROPRIATIONS

FISCAL NOTE

HOUSE BILL NO. 239

PRINTERS NO. 2005

PRIME SPONSOR: Toepel

COST / (SAVINGS)

FUND	FY 2016/17	FY 2017/18
General Fund	See Fiscal Impact	See Fiscal Impact

SUMMARY: House Bill 239, Printer's Number 261, the Rare Disease Advisory Council Act, creates the Rare Disease Advisory Council to study the incidence and prevalence of rare diseases in Pennsylvania. This legislation is effective immediately and sunsets on June 30, 2025.

ANALYSIS: HB 239 creates the Rare Disease Advisory Council to study the incidence and prevalence of rare diseases. The Rare Disease Advisory Council consists of the following members:

- The Secretary of Health or an authorized designee;
- The heads of State agencies that may be concerned with the provision of care to persons with rare diseases, or their designees.
 - At a minimum, members shall include the Secretary of Human Services and the Secretary of Education or their respective designees;
- The Insurance Commissioner or an authorized designee;
- Public members to be appointed by the Secretary of Health within 60 days, who shall include:
 - Three physicians licensed to practice in PA who have expertise in the diagnosis and management of patients with rare diseases, one of whom shall be a pediatrician who provides care to children with rare diseases;
 - Two registered professional nurses or nurse practitioners licensed in PA who have expertise in providing care to patients with rare diseases;
 - An epidemiologist licensed in PA who has expertise in the incidence, prevalence and control of rare diseases;
 - Two representatives of hospitals in PA, one of which must be a research hospital;
 - Two representatives of the health insurance industry;
 - Two representatives involved in the biopharmaceutical industry;
 - Two representatives of the scientific community who are engaged in rare disease research;
 - Two parents, each of whom has a child with a rare disease, not of the same family;
 - Two individuals with rare diseases; and
 - Representatives of two rare disease-specific patient organizations that operate within PA.

At any time, the advisory council may advise DOH on additional at-large appointments that may be necessary to carry out the duties of the council. The advisory council is required to meet a minimum of three times each year, with the initial meeting to be held within 90 days of the bill's effective date. Members are permitted to participate by teleconference.

The duties of the Rare Disease Advisory Council include:

- Research and determine the most appropriate method to collect rare disease data and information concerning individuals with rare diseases, as the advisory council deems necessary and appropriate to conduct comprehensive surveys of rare diseases diagnosed in PA, subject to all applicable privacy laws and protections;
- Ensure that the duties are carried out in a manner that is coordinated and interoperable with other similar research being conducted at the Federal and State level;
- Research and identify priorities relating to the quality and cost effectiveness of and access to treatment and other services provided to individuals with rare diseases in PA and develop policy recommendations on those issues;
- Identify best practices in other states and at the national level for rare disease management, monitoring and surveillance, education, detection, diagnosis, information and care to improve these functions and capabilities relative to rare diseases within PA;
- Develop effective strategies to raise public awareness of rare diseases within PA;
- Coordinate the development of a task force, comprised of members of the advisory council and other individuals as may be necessary and appropriate to facilitate the development and publication of the required comprehensive report.

Prior to appointing members of the advisory council, DOH is required to research and report to the General Assembly, within 30 days of the bill's effective date, existing sources of funding that may be used to finance the formation and operation of the advisory council.

Preliminary Report:

- Within 12 months of the effective date, the advisory council is required to deliver to the Senate Public Health and Welfare Committee and the House Health Committee a preliminary report on the work of the advisory council, including a summary of the accomplishments of the advisory council since its formation and the status of its work in preparation of the required comprehensive report.

Comprehensive Report:

- Within two years of the bill's effective date, the advisory council is required to deliver to the Senate Health and Human Services Committee and the House Health Committee a comprehensive report, which shall include the incidence and prevalence of rare diseases within PA and the needs of the rare disease community within PA and the actions necessary and feasible to address those needs.

Biennial Reports:

- The advisory council is required to report biennially to DOH and to the Senate Health and Human Services Committee and the House Health Committee on the activities of the council and its findings and recommendations on issues relating to the management,

monitoring and surveillance, education, detection, diagnosis, information and care regarding rare diseases in the PA, including the quality and cost effectiveness of care, access to treatment and other relevant services for individuals affected by rare diseases.

All required reports will be made available to the public.

FISCAL IMPACT: Enactment of this legislation should have minimal fiscal impact on Commonwealth funds. While public members of the Advisory Council may be reimbursed for travel and other miscellaneous expenses, DOH is required to research and report existing sources of funding that can be used to support the Advisory Council. In addition, council members are permitted to participate by teleconference which should reduce expenses.

PREPARED BY: Ann Bertolino
House Appropriations Committee (R)

DATE: June 29, 2017

Estimates are calculated using the best information available. Actual costs and revenue impact incurred may vary from estimates.