



# SENATE OF PENNSYLVANIA BILL SUMMARY

## House Bill 239 Printer's No. 261

Prime Sponsor: Toepel  
Committee: Health and Human Services

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### **SYNOPSIS:**

Enacts the Rare Disease Advisory Council Act (the "Act"). The Act establishes the Rare Disease Advisory Council (the "Council") within the Department of Health ("DOH").

### **SUMMARY:**

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

The Council is established and consists of the following:

- The Secretary of DOH
- 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 members as recommended by the Council

The Secretary of the DOH shall appoint the Chairperson and the public members.

Public members shall serve without compensation but may be reimbursed for expenses.

The Council shall meet a minimum of three times per year and may request assistance from any State or local government agency and may receive staff from the DOH.

The purpose of the 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 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 the 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

Prior to appointing members to the Council, DOH is to research and report to the General Assembly existing sources of funding for the Council. The Council is also authorized to apply for federal grants, private funds and other sources of funding.

The council shall deliver to the General Assembly a preliminary report (within 12 months) and a final report (within two years). The final report shall include the incidence and prevalence of rare diseases and the needs of the rare disease community. The Council shall also report biennially to the general assembly on the activities of the Council and its findings and recommendations.

The Act expires June 30, 2025.

Effective Date: Immediately

## **BILL HISTORY:**

In the House

Referred to HEALTH, Feb. 1, 2017

Reported as committed, April 4, 2017

First consideration, April 4, 2017

Laid on the table, April 4, 2017

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Removed from table, May 8, 2017  
Second consideration, May 9, 2017  
Re-committed to APPROPRIATIONS, May 9, 2017  
Re-reported as committed, May 10, 2017  
Third consideration and final passage, May 10, 2017 (196-0)

In the Senate

Referred to HEALTH AND HUMAN SERVICES, May 15, 2017

Prepared by: Cortez 6/8/2017