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OHIO LEGISLATIVE SERVICE COMMISSION

Office of Research
and Drafting

Legislative Budget
Office

H.B. 412
133rd General Assembly

Fiscal Note & Local Impact Statement

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Version: As Passed by the House

Primary Sponsors: Reps. Clites and Ginter

Local Impact Statement Procedure Required: No

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Highlights

- The Ohio Department of Health (ODH) will experience an increase in costs to produce the required report on the incidence of rare diseases in Ohio. Total costs will depend on a number of factors including the number of diseases analyzed, the number of individuals impacted, the current availability of this information, and the method of data collection.
- State agencies participating on the Rare Disease Advisory Council may realize a minimal cost related to reimbursements for actual and necessary expenses incurred by Council members.

Detailed Analysis

Rare Disease Advisory Council

The bill establishes the Rare Disease Advisory Council for the purpose of advising the General Assembly regarding research, diagnosis, and treatment efforts related to rare diseases across the state. The bill outlines the Council's membership and duties, which are to prepare and submit a report to the General Assembly detailing (1) the coordination of statewide efforts for studying the incidence of rare diseases in this state, (2) the Council's findings and recommendations regarding rare disease research and care in this state, and (3) efforts to promote collaboration among rare disease organizations, clinicians, academic research institutions, and the General Assembly to better understand the incidence of rare diseases. The Council is to consist of 25 members and is required to meet at least quarterly. Members are to serve without compensation except to the extent that serving on the Council is considered part of the member's regular duties of employment. The Council is required to reimburse each member for actual and necessary expenses incurred in the performance of the member's official duties.

Fiscal impact

The bill should not have a significant fiscal impact for any state agency with staff members who are appointed to the Council, though staff time may be spent performing official Council business.¹ The bill indicates that Council members may be reimbursed for actual and necessary expenses incurred; LSC staff assumes that participating state agencies would provide this reimbursement.

Ohio Department of Health reporting requirements

The bill also requires the Director of Health, not later than three years after the effective date, to publish a report detailing the incidence of rare diseases in Ohio. The report is required to include data regarding individuals who have been diagnosed with rare diseases, disaggregated by gender, race, ethnicity, socioeconomic status, and type of insurance coverage. After the first report, subsequent reports are required to be published every two years.

Fiscal impact

The Ohio Department of Health (ODH) will experience an increase in costs to produce the required report. The costs will depend on various factors including the number of diseases analyzed, the number of individuals impacted, the current availability of this information, and the method of data collection. ODH anticipates that there could be initial costs of about \$500,000 to develop a database or to modify an existing one to collect this data. In addition, ODH anticipates that one-half of a full-time equivalent employee would be needed to monitor the data, respond to questions, etc. It is possible that there could be indirect costs to government entities such as government-owned hospitals, if ODH requested data concerning rare diseases from these entities.

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¹ State agencies to be represented on the Council include the departments of Health, Medicaid, Insurance, as well as the Commission on Minority Health. In addition, members also include the Governor or the Governor's designee, two members of the Senate, and two members of the House of Representatives.