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H.B. 412*
133rd General Assembly

Bill Analysis

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Version: As Reported by House Health

Primary Sponsors: Reps. Clites and Ginter

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SUMMARY

- Establishes the Rare Disease Advisory Council.
- Requires the Department of Health to publish periodic reports detailing the incidence of rare diseases in Ohio.

DETAILED ANALYSIS

Rare Disease Advisory Council

The bill establishes the Rare Disease Advisory Council, which is tasked with advising the General Assembly regarding research, diagnosis, and treatment efforts related to rare diseases in Ohio.¹ Under the bill, a rare disease is “a disease or condition that affects fewer than 200,000 people living in the United States.”²

Membership and appointment procedures

The Advisory Council consists of 25 members. The following 20 members are to be appointed by the Governor:

- An individual who is a medical researcher with experience researching rare diseases;
- An individual who is a representative of an academic research institution in the state that receives funding for rare disease research;

* This analysis was prepared before the report of the House Health Committee appeared in the House Journal. Note that the legislative history may be incomplete.

¹ R.C. 103.60(B).

² R.C. 103.60(A).

- A licensed physician who has experience researching, diagnosing, and treating rare diseases;
- A licensed registered nurse who has experience providing nursing care to patients with rare diseases;
- A licensed genetic counselor who is currently practicing at a children's hospital;
- Three members of the public who are living with a rare disease or are the representative of an individual living with a rare disease;
- One representative of a national organization representing patients with a rare disease;
- One representative of a rare disease foundation operating in Ohio;
- Two representatives of the Department of Health, one of whom is a representative of the Children with Medical Handicaps Program;
- One representative of the Department of Medicaid;
- One representative of the Department of Insurance;
- One representative of the Commission on Minority Health;
- One representative of the Ohio Hospital Association;
- One representative of Ohio health insurers;
- One representative of BioOhio;
- One representative of the Association of Ohio Health Commissioners;
- One representative of the Pharmaceutical Research and Manufacturers of America.

The remaining five members of the Advisory Council include the Governor or the Governor's designee, two members of the Senate (one from the majority party and one from the minority party) both appointed by the President of the Senate, and two members of the House of Representatives (one from the majority party and one from the minority party) both appointed by the Speaker of the House of Representatives.³

The bill requires initial appointments to the Advisory Council to be made within 30 days after the bill's effective date. Thereafter, appointments to the Advisory Council occur every two years, not later than 30 days after the commencement of the first regular session of each General Assembly. A member appointed to the Advisory Council will serve as a member until appointments are made in the subsequent General Assembly. A member of the Advisory Council may be reappointed, but no member may serve more than four consecutive terms on the Advisory Council.⁴

³ R.C. 103.60(C).

⁴ R.C. 103.60(D).

Operation and reporting requirements

Under the bill, the Advisory Council is required to annually select from among the members a chairperson or co-chairpersons. The Advisory Council will meet at the call of the chairperson, who is required to provide members with at least five days' written notice of any meeting. The Advisory Council must meet at least quarterly.⁵

Members of the Advisory Council serve without compensation except to the extent that serving on the Advisory Council is considered part of the member's regular duties of employment. However, a member may be reimbursed for actual and necessary expenses incurred in the performance of the member's official duties as a part of the Advisory Council.⁶

The bill requires the Advisory Council to prepare and submit a report to the General Assembly prior to the expiration of each term. The report must include details of the following:

- The coordination of statewide efforts for studying the incidence of rare diseases in Ohio;
- The Advisory Council's findings and recommendations regarding rare disease research and care in Ohio;
- Efforts to promote collaboration among rare disease organizations, clinicians, academic research institutions, and the General Assembly to better understand the incidence of rare diseases in Ohio.⁷

Department of Health reporting

The bill also requires the Director of Health 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. The Director's first report must be published within three years after the bill's effective date and subsequent reports published every two years thereafter.⁸

HISTORY

Action	Date
Introduced	11-13-19
Reported, H. Health	---

H0412-RH-133/ks

⁵ R.C. 103.60(F) and (G).

⁶ R.C. 103.60(H).

⁷ R.C. 103.60(E).

⁸ R.C. 3701.051.