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H.B. 412
133rd General Assembly

Final Analysis

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Version: As Passed by the General Assembly

Primary Sponsors: Reps. Clites and Ginter

Effective date: Emergency: Emergency Response Commission's authority to exempt local exercises is effective December 21, 2020; establishment of Rare Disease Advisory Council is effective March 24, 2021

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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.
- Authorizes the Emergency Response Commission to exempt, for a period of one year, a local emergency planning committee from conducting an exercise of its chemical emergency response and preparedness plan if conducting the exercise is likely to affect public health or safety or the environment.

DETAILED ANALYSIS

Rare Disease Advisory Council

The act 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 act, a rare disease is "a disease or condition that affects fewer than 200,000 people living in the United States."²

¹ R.C. 103.60(B).

² R.C. 103.60(A).

Membership and appointment procedures

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

- A medical researcher with experience researching rare diseases;
- A representative of an Ohio academic research institution that receives funding for rare disease research;
- 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 practices 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 represents 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; and
- One representative of the Pharmaceutical Research and Manufacturers of America.

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

The act requires initial appointments to the Advisory Council to be made by April 23, 2021. Thereafter, appointments to the Advisory Council occur every two years, within

³ R.C. 103.60(C).

30 days after the commencement of the first regular session of each General Assembly. A member serves until appointments are made in the subsequent General Assembly. A member may be reappointed, but no member may serve more than four consecutive terms on the Advisory Council.⁴

Operation and reporting

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

Members 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 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;
- Findings and recommendations regarding rare disease research and care in Ohio; and
- 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 act also requires the Director of Health to publish a report detailing the incidence of rare diseases in Ohio. The report must 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 by March 24, 2024, and subsequent reports published every two years thereafter.⁸

Chemical emergency response and preparedness plans

The act authorizes the Emergency Response Commission, by order, to exempt a local emergency planning committee of an emergency planning district from the requirement to conduct an exercise of its chemical emergency response and preparedness plan at least

⁴ R.C. 103.60(D).

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.

annually. An exemption may not last for more than one year. Under continuing law, each emergency planning committee must prepare and submit to the Commission a chemical emergency response and preparedness plan for the district.⁹

HISTORY

Action	Date
Introduced	11-13-19
Reported, H. Health	02-05-20
Passed House (95-0)	02-05-20
Reported, S. Health, Human Services & Medicaid	12-01-20
Passed Senate (33-0)	12-02-20
House concurred in Senate amendments (85-0)	12-08-20

20-HB412-133/ts

⁹ R.C. 3750.04(C) and (D).