

# AN ACT

To amend section 3750.04 and to enact sections 103.60 and 3701.051 of the Revised Code to establish the Rare Disease Advisory Council, to authorize the Emergency Response Commission to exempt a local emergency planning committee from conducting certain annual exercises, and to declare an emergency.

*Be it enacted by the General Assembly of the State of Ohio:*

SECTION 1. That section 3750.04 be amended and sections 103.60 and 3701.051 of the Revised Code be enacted to read as follows:

Sec. 103.60. (A) As used in this section, "rare disease" means a disease or condition that affects fewer than 200,000 people living in the United States.

(B) There is hereby created the rare disease advisory council. The purpose of the council is to advise the general assembly regarding research, diagnosis, and treatment efforts related to rare diseases across the state.

(C) The council shall consist of the following twenty-five members:

(1) The following members appointed by the governor:

(a) One individual who is a medical researcher with experience researching rare diseases;

(b) One individual who represents an academic research institution in this state that receives funding for rare disease research;

(c) One individual authorized under Chapter 4731. of the Revised Code to practice medicine and surgery or osteopathic medicine and surgery who has experience researching, diagnosing, and treating rare diseases;

(d) One individual authorized under Chapter 4723. of the Revised Code to practice nursing as a registered nurse who has experience providing nursing care to patients with rare diseases;

(e) One individual authorized under Chapter 4778. of the Revised Code to practice as a genetic counselor who is currently practicing at a children's hospital;

(f) Three members of the public who are living with a rare disease or represent an individual living with a rare disease;

(g) One representative of a national organization representing patients with a rare disease;

(h) One representative of a rare disease foundation operating in this state;

(i) Two representatives of the department of health, one of whom is a representative of the children with medical handicaps program;

(j) One representative of the department of medicaid;

(k) One representative of the department of insurance;

(l) One representative of the commission on minority health;

(m) One representative of the Ohio hospital association;

(n) One representative of Ohio health insurers;

(o) One representative of bioOhio;

(p) One representative of the association of Ohio health commissioners;

(q) One representative of the pharmaceutical research and manufacturers of America.

(2) Two members of the senate, one from the majority party and one from the minority party, both appointed by the president of the senate;

(3) 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;

(4) The governor or the governor's designee.

(D)(1) Not later than thirty days after the effective date of this section, initial appointments shall be made to the council. Thereafter, appointments shall be made every two years, not later than thirty days after the commencement of the first regular session of each general assembly.

(2) Each member shall serve on the council until appointments are made following the commencement of the next general assembly. Members may be reappointed; however, no member shall serve more than four consecutive terms on the council.

(E) Prior to the expiration of each term, the council shall prepare and submit a report to the general assembly detailing the following:

(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;

(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 in this state.

(F) The council shall annually select from among its members a chairperson or co-chairpersons.

(G) The council shall meet at the call of the chairperson, but not less than quarterly. A majority of the members of the council shall constitute a quorum. The chairperson shall provide members with at least five days written notice of all meetings.

(H) Members shall 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 shall reimburse each member for actual and necessary expenses incurred in the performance of the member's official duties.

Sec. 3701.051. (A) As used in this section, "rare disease" has the same meaning as in section 103.60 of the Revised Code.

(B) Not later than three years after the effective date of this section, the director of health shall publish a report detailing the incidence of rare diseases in this state, with subsequent reports published every two years thereafter. To the extent possible, the reports shall include data regarding individuals who have been diagnosed with a rare disease disaggregated by gender, race, ethnicity, socioeconomic status, and type of insurance coverage.

Sec. 3750.04. (A) Within ninety days after the effective date of this section, the local emergency planning committee of each emergency planning district shall prepare and submit to the

emergency response commission a chemical emergency response and preparedness plan for the district. The district's plan shall contain all of the following:

(1) An identification of each facility within the district that meets either of the following qualifications:

(a) Has an extremely hazardous substance present at the facility in an amount that exceeds the threshold planning quantity for the substance established in rules adopted under division (B)(1)(a) or (C)(5) of section 3750.02 of the Revised Code;

(b) Is required to participate in the emergency planning process by an order issued under division (A) of section 3750.05 of the Revised Code.

(2) An identification of all facilities within the district that are contributing or subjected to additional risk due to their proximity to facilities identified under division (A)(1) of this section;

(3) An identification of routes likely to be used for the transportation of extremely hazardous substances to and from each facility identified under division (A)(1) of this section;

(4) The methods and procedures to be followed by owners and operators of facilities identified under division (A)(1) of this section and by local emergency response and medical personnel to respond to releases of extremely hazardous substances;

(5) The designation of a community emergency coordinator for the district, identification of the facility emergency coordinator for each facility identified under division (A)(1) of this section, and identification of the heads of the emergency response organizations for designated areas or political subdivisions within the district;

(6) An identification of procedures for reliable, effective, and timely notification and communication among emergency responders within the district and to the public in the event of a release of an extremely hazardous substance from a facility identified under division (A)(1) of this section;

(7) The development of methods for determining the occurrence of a release of an extremely hazardous substance from each facility identified under division (A)(1) of this section and for identifying the geographic area or population likely to be affected by such a release;

(8) A composite statement of specialized equipment, facilities, personnel, and emergency response organizations available within the district to respond to releases of extremely hazardous substances;

(9) The development of evacuation plans including, but not limited to, provisions for a precautionary evacuation and for alternative traffic routes in the event of a release of an extremely hazardous substance from a facility identified under division (A)(1) of this section;

(10) A plan for mutual aid to other emergency planning districts and for the allocation of emergency response facilities, equipment, and personnel for responding to releases of extremely hazardous substances;

(11) A plan for the development or provision of training programs, seminars, and other forms of educational programs for the personnel of facilities identified under division (A)(1) of this section, emergency response personnel of political subdivisions within the district, and medical personnel;

(12) The development of methods and schedules for exercising the plan;

(13) Such other information as the commission requires by rules adopted under division (B)(2)(a) of section 3750.02.

The committee shall base its plan on information obtained from the commission, the environmental protection agency, emergency management agencies of the state and political subdivisions within the district, and facilities identified under division (A)(1) of this section.

(B) The committee annually shall submit the plan to the commission not later than the seventeenth day of October for review and concurrence. The commission shall review the plan to ensure that it complies with division (A) of this section and rules adopted under divisions (B)(2)(a) and (b) of section 3750.02 of the Revised Code, and to ensure that it is coordinated with the plans of adjoining districts. The commission shall endeavor to review each such plan and provide notice of concurrence with the plan or of recommendations for modifications to it within sixty days after its submission to the commission. The commission may assign the highest priority for review to plans applying to geographic areas having the greatest number of facilities that pose the greatest risk of harm to the public health or safety or to the environment.

If the commission finds that the plan submitted by a committee complies with division (A) of this section and rules adopted under divisions (B)(2)(a) and (b) of section 3750.02 of the Revised Code and is coordinated with the plans of adjoining districts, the commission shall, within sixty days after submission of the plan, issue an order in accordance with section 3750.18 of the Revised Code concurring with the plan. If the commission finds that the plan submitted by a committee does not comply with division (A) of this section and rules adopted under divisions (B)(2)(a) and (b) of section 3750.02 of the Revised Code or is not coordinated with the plans of adjoining districts, the commission shall, by issuance of such an order within that sixty-day period, refuse to concur with the plan and direct the committee to submit a modified plan that complies with those requirements within a reasonable time, not exceeding sixty days, after issuance of the order.

(C) ~~Each~~ Except as provided in division (D) of this section, the committee shall conduct an exercise of its plan at least annually. The committee shall notify the commission at least thirty days before each such exercise, and the commission shall observe each such exercise. The commission shall review each such exercise in accordance with the rules adopted under division (B)(2)(b) of section 3750.02 of the Revised Code and shall either concur with the conduct of the exercise or direct the committee to make modifications in the exercise of the plan in accordance with those rules.

If the commission finds that the committee's exercise of its plan complies with the criteria established in rules adopted under division (B)(2)(b) of section 3750.02 of the Revised Code, the commission shall issue an order in accordance with section 3750.18 of the Revised Code concurring with the conduct of the exercise. If the commission finds that the committee's exercise of its plan does not comply with those criteria, the commission shall, by issuance of such an order, refuse to concur with the conduct of the exercise and direct the committee to make modifications in the exercise of the plan that comply with those rules.

Each committee shall annually, or more frequently if changed circumstances in the district or at any facility in the district so require, review the plan of the district. The review shall include, without limitation, an evaluation of the need for funds, personnel, training, equipment, and facilities to develop, revise, implement, and exercise the plan and recommendations and requests to the commission regarding any additional funds that may be needed for those purposes and the means for providing them.

(D) The commission, by order, may exempt a committee from conducting an exercise of its

plan if, in the determination of the commission, conducting an exercise is likely to have an adverse effect on the public health or safety or the environment of its emergency planning district. Such an exemption shall not last for more than one year.

SECTION 2. That existing section 3750.04 of the Revised Code is hereby repealed.

SECTION 3. Section 3750.04 of the Revised Code, as amended by this act, is hereby declared to be an emergency measure necessary for the immediate preservation of the public peace, health, and safety. The reason for such necessity is that immediate action is crucial to protecting public health during the ongoing COVID-19 pandemic. Therefore, section 3750.04 of the Revised Code, as amended by this act, shall go into immediate effect.

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*Speaker* \_\_\_\_\_ *of the House of Representatives.*

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*President* \_\_\_\_\_ *of the Senate.*

Passed \_\_\_\_\_, 20\_\_\_\_

Approved \_\_\_\_\_, 20\_\_\_\_

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*Governor.*

The section numbering of law of a general and permanent nature is complete and in conformity with the Revised Code.

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*Director, Legislative Service Commission.*

Filed in the office of the Secretary of State at Columbus, Ohio, on the \_\_\_\_ day of \_\_\_\_\_, A. D. 20 \_\_\_\_.

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*Secretary of State.*

File No. \_\_\_\_\_ Effective Date \_\_\_\_\_