## As Passed by the Senate

133rd General Assembly

Regular Session

Am. Sub. H. B. No. 412

2019-2020

**Representatives Clites, Ginter** 

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# A BILL

То	amend section 3750.04 and to enact sections	1
	103.60 and 3701.051 of the Revised Code to	2
	establish the Rare Disease Advisory Council, to	3
	authorize the Emergency Response Commission to	4
	exempt a local emergency planning committee from	5
	conducting certain annual exercises, and to	6
	declare an emergency.	7

## BE IT ENACTED BY THE GENERAL ASSEMBLY OF THE STATE OF OHIO:

Section 1. That section 3750.04 be amended and sections	8
103.60 and 3701.051 of the Revised Code be enacted to read as	9
follows:	10

Sec. 103.60. (A) As used in this section, "rare disease"	11	
means a disease or condition that affects fewer than 200,000		
people living in the United States.		
(D) There is hereby erected the rare disease eduicery	14	
(B) There is hereby created the rare disease advisory		
council. The purpose of the council is to advise the general	15	
assembly regarding research, diagnosis, and treatment efforts	16	
related to rare diseases across the state.	17	
(C) The council shall consist of the following twenty-five	18	
members:	19	
	0.0	
(1) The following members appointed by the governor:	20	
(a) One individual who is a medical researcher with	21	
experience researching rare diseases;	22	
	2.2	
(b) One individual who represents an academic research	23	
institution in this state that receives funding for rare disease	24	
research;	25	
(c) One individual authorized under Chapter 4731. of the	26	
Revised Code to practice medicine and surgery or osteopathic	27	
medicine and surgery who has experience researching, diagnosing,		
and treating rare diseases;		
(d) One individual authomized under Chapter (1722) of the	20	
(d) One individual authorized under Chapter 4723. of the	30	
Revised Code to practice nursing as a registered nurse who has	31	
experience providing nursing care to patients with rare	32	
<u>diseases;</u>	33	
(e) One individual authorized under Chapter 4778. of the	34	
Revised Code to practice as a genetic counselor who is currently	35	
practicing at a children's hospital;	36	
	25	
(f) Three members of the public who are living with a rare	37	
disease or represent an individual living with a rare disease;	38	

(g) One representative of a national organization	39
representing patients with a rare disease;	40
(h) One representative of a rare disease foundation	41
operating in this state;	42
(i) Two representatives of the department of health, one	43
of whom is a representative of the children with medical	44
handicaps program;	45
(j) One representative of the department of medicaid;	46
(k) One representative of the department of insurance;	47
(1) One representative of the commission on minority	48
health;	49
(m) One representative of the Ohio hospital association;	50
(n) One representative of Ohio health insurers;	51
(o) One representative of bioOhio;	52
(p) One representative of the association of Ohio health	53
<pre>commissioners;</pre>	54
(q) One representative of the pharmaceutical research and	55
manufacturers of America.	56
(2) Two members of the senate, one from the majority party	57
and one from the minority party, both appointed by the president	58
of the senate;	59
(3) Two members of the house of representatives, one from	60
the majority party and one from the minority party, both	61
appointed by the speaker of the house of representatives;	62
(4) The governor or the governor's designee.	63
(D)(1) Not later than thirty days after the effective date	64

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of this section, initial appointments shall be made to the	65	
council. Thereafter, appointments shall be made every two years,	66	
not later than thirty days after the commencement of the first	67	
regular session of each general assembly.	68	
(2) Each member shall serve on the council until	69	
appointments are made following the commencement of the next	70	
general assembly. Members may be reappointed; however, no member	71	
shall serve more than four consecutive terms on the council.	72	
(E) Prior to the expiration of each term, the council	73	
shall prepare and submit a report to the general assembly	74	
detailing the following:	75	
(1) The coordination of statewide efforts for studying the	76	
incidence of rare diseases in this state;	77	
(2) The council's findings and recommendations regarding	78	
rare disease research and care in this state;		
(3) Efforts to promote collaboration among rare disease	80	
organizations, clinicians, academic research institutions, and	81	
the general assembly to better understand the incidence of rare		
diseases in this state.		
(F) The council shall annually select from among its	84	
members a chairperson or co-chairpersons.		
(G) The council shall meet at the call of the chairperson,	86	
but not less than quarterly. A majority of the members of the	87	
council shall constitute a quorum. The chairperson shall provide	88	
members with at least five days written notice of all meetings.	89	
(H) Members shall serve without compensation except to the	90	
extent that serving on the council is considered part of the	91	
member's regular duties of employment. The council shall	92	

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reimburse each member for actual and necessary expenses incurred	93
in the performance of the member's official duties.	94
Sec. 3701.051. (A) As used in this section, "rare disease"	95
has the same meaning as in section 103.60 of the Revised Code.	96
(B) Not later than three years after the effective date of	97
this section, the director of health shall publish a report	98
detailing the incidence of rare diseases in this state, with	99
subsequent reports published every two years thereafter. To the	100
extent possible, the reports shall include data regarding	101
individuals who have been diagnosed with a rare disease	102
disaggregated by gender, race, ethnicity, socioeconomic status,	103
and type of insurance coverage.	104
Sec. 3750.04. (A) Within ninety days after the effective	105
date of this section, the local emergency planning committee of	106
each emergency planning district shall prepare and submit to the	107
emergency response commission a chemical emergency response and	108
preparedness plan for the district. The district's plan shall	109
contain all of the following:	110
(1) An identification of each facility within the district	111
that meets either of the following qualifications:	112
(a) Has an extremely hazardous substance present at the	113
facility in an amount that exceeds the threshold planning	114
quantity for the substance established in rules adopted under	115
division (B)(1)(a) or (C)(5) of section 3750.02 of the Revised	116
Code;	117
(b) Is required to participate in the emergency planning	118
process by an order issued under division (A) of section 3750.05	119
of the Revised Code.	120
(2) An identification of all facilities within the	121

district that are contributing or subjected to additional risk 122 due to their proximity to facilities identified under division 123 (A) (1) of this section; 124

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

(5) The designation of a community emergency coordinator
for the district, identification of the facility emergency
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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;
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(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
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occurrence of a release of an extremely hazardous substance from
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each facility identified under division (A) (1) of this section
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and for identifying the geographic area or population likely to
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be affected by such a release;

(8) A composite statement of specialized equipment,facilities, personnel, and emergency response organizations150

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available within the district to respond to releases of	151
extremely hazardous substances;	152
(9) The development of evacuation plans including, but not	153
limited to, provisions for a precautionary evacuation and for	154
alternative traffic routes in the event of a release of an	155
extremely hazardous substance from a facility identified under	156
division (A)(1) of this section;	157
(10) A plan for mutual aid to other emergency planning	158
districts and for the allocation of emergency response	159
facilities, equipment, and personnel for responding to releases	160
of extremely hazardous substances;	161
(11) A plan for the development or provision of training	162
programs, seminars, and other forms of educational programs for	163
the personnel of facilities identified under division (A)(1) of	164
this section, emergency response personnel of political	165
subdivisions within the district, and medical personnel;	166
(12) The development of methods and schedules for	167
exercising the plan;	168
exercising the plan,	100
(13) Such other information as the commission requires by	169
rules adopted under division (B)(2)(a) of section 3750.02.	170
The committee shall base its plan on information obtained	171
from the commission, the environmental protection agency,	172
emergency management agencies of the state and political	173
subdivisions within the district, and facilities identified	174
under division (A)(1) of this section.	175
(B) The committee annually shall submit the plan to the	176
commission not later than the seventeenth day of October for	177
review and concurrence. The commission shall review the plan to	178

ensure that it complies with division (A) of this section and

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rules adopted under divisions (B)(2)(a) and (b) of section 180 3750.02 of the Revised Code, and to ensure that it is 181 coordinated with the plans of adjoining districts. The 182 commission shall endeavor to review each such plan and provide 183 notice of concurrence with the plan or of recommendations for 184 modifications to it within sixty days after its submission to 185 the commission. The commission may assign the highest priority 186 for review to plans applying to geographic areas having the 187 greatest number of facilities that pose the greatest risk of 188 harm to the public health or safety or to the environment. 189

190 If the commission finds that the plan submitted by a committee complies with division (A) of this section and rules 191 adopted under divisions (B)(2)(a) and (b) of section 3750.02 of 192 the Revised Code and is coordinated with the plans of adjoining 193 districts, the commission shall, within sixty days after 194 submission of the plan, issue an order in accordance with 195 section 3750.18 of the Revised Code concurring with the plan. If 196 the commission finds that the plan submitted by a committee does 197 not comply with division (A) of this section and rules adopted 198 under divisions (B)(2)(a) and (b) of section 3750.02 of the 199 Revised Code or is not coordinated with the plans of adjoining 200 districts, the commission shall, by issuance of such an order 201 within that sixty-day period, refuse to concur with the plan and 202 direct the committee to submit a modified plan that complies 203 with those requirements within a reasonable time, not exceeding 204 sixty days, after issuance of the order. 205

(C) Each Except as provided in division (D) of this
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<u>section, the committee shall conduct an exercise of its plan at</u>
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least annually. The committee shall notify the commission at
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least thirty days before each such exercise, and the commission
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shall observe each such exercise. The commission shall review
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each such exercise in accordance with the rules adopted under211division (B)(2)(b) of section 3750.02 of the Revised Code and212shall either concur with the conduct of the exercise or direct213the committee to make modifications in the exercise of the plan214in accordance with those rules.215

If the commission finds that the committee's exercise of 216 its plan complies with the criteria established in rules adopted 217 under division (B)(2)(b) of section 3750.02 of the Revised Code, 218 the commission shall issue an order in accordance with section 219 3750.18 of the Revised Code concurring with the conduct of the 220 221 exercise. If the commission finds that the committee's exercise of its plan does not comply with those criteria, the commission 222 shall, by issuance of such an order, refuse to concur with the 223 conduct of the exercise and direct the committee to make 224 modifications in the exercise of the plan that comply with those 225 rules. 226

Each committee shall annually, or more frequently if 227 changed circumstances in the district or at any facility in the 228 district so require, review the plan of the district. The review 229 230 shall include, without limitation, an evaluation of the need for funds, personnel, training, equipment, and facilities to 231 develop, revise, implement, and exercise the plan and 232 recommendations and requests to the commission regarding any 233 additional funds that may be needed for those purposes and the 234 means for providing them. 235

(D) The commission, by order, may exempt a committee from236conducting an exercise of its plan if, in the determination of237the commission, conducting an exercise is likely to have an238adverse effect on the public health or safety or the environment239of its emergency planning district. Such an exemption shall not240

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### last for more than one year.

Section 2.	That existing	section 375	0.04 of the	Revised 242	2
Code is hereby r	epealed.			243	3

Section 3. Section 3750.04 of the Revised Code, as amended 244 by this act, is hereby declared to be an emergency measure 245 necessary for the immediate preservation of the public peace, 246 health, and safety. The reason for such necessity is that 247 immediate action is crucial to protecting public health during 248 the ongoing COVID-19 pandemic. Therefore, section 3750.04 of the 249 Revised Code, as amended by this act, shall go into immediate 250 effect. 251