

As Reported by the House Health Committee

133rd General Assembly

Regular Session

2019-2020

Am. H. B. No. 412

Representatives Clites, Ginter

Cosponsors: Representatives Blair, Boggs, Boyd, Crawley, Crossman, Galonski, Hambley, Miller, A., Miller, J., Smith, K., Lepore-Hagan, Lipps, Liston, Miranda, O'Brien, Patterson, Romanchuk, Russo, Scherer, Sobecki, Strahorn, Upchurch, Weinstein, West

A BILL

To enact sections 103.60 and 3701.051 of the 1
Revised Code to establish the Rare Disease 2
Advisory Council. 3

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

Section 1. That sections 103.60 and 3701.051 of the 4
Revised Code be enacted to read as follows: 5

Sec. 103.60. (A) As used in this section, "rare disease" 6
means a disease or condition that affects fewer than 200,000 7
people living in the United States. 8

(B) There is hereby created the rare disease advisory 9
council. The purpose of the council is to advise the general 10
assembly regarding research, diagnosis, and treatment efforts 11
related to rare diseases across the state. 12

(C) The council shall consist of the following twenty-five 13
members: 14

(1) The following members appointed by the governor: 15

- (a) One individual who is a medical researcher with experience researching rare diseases; 16
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- (b) One individual who represents an academic research institution in this state that receives funding for rare disease research; 18
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- (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; 21
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- (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; 25
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- (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; 29
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- (f) Three members of the public who are living with a rare disease or represent an individual living with a rare disease; 32
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- (g) One representative of a national organization representing patients with a rare disease; 34
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- (h) One representative of a rare disease foundation operating in this state; 36
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- (i) Two representatives of the department of health, one of whom is a representative of the children with medical handicaps program; 38
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- (j) One representative of the department of medicaid; 41
- (k) One representative of the department of insurance; 42

<u>(l) One representative of the commission on minority health;</u>	43 44
<u>(m) One representative of the Ohio hospital association;</u>	45
<u>(n) One representative of Ohio health insurers;</u>	46
<u>(o) One representative of bioOhio;</u>	47
<u>(p) One representative of the association of Ohio health commissioners;</u>	48 49
<u>(q) One representative of the pharmaceutical research and manufacturers of America.</u>	50 51
<u>(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;</u>	52 53 54
<u>(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;</u>	55 56 57
<u>(4) The governor or the governor's designee.</u>	58
<u>(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.</u>	59 60 61 62 63
<u>(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.</u>	64 65 66 67
<u>(E) Prior to the expiration of each term, the council shall prepare and submit a report to the general assembly</u>	68 69

<u>detailing the following:</u>	70
<u>(1) The coordination of statewide efforts for studying the incidence of rare diseases in this state;</u>	71 72
<u>(2) The council's findings and recommendations regarding rare disease research and care in this state;</u>	73 74
<u>(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.</u>	75 76 77 78
<u>(F) The council shall annually select from among its members a chairperson or co-chairpersons.</u>	79 80
<u>(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.</u>	81 82 83 84
<u>(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.</u>	85 86 87 88 89
<u>Sec. 3701.051.</u> (A) <u>As used in this section, "rare disease" has the same meaning as in section 103.60 of the Revised Code.</u>	90 91
<u>(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</u>	92 93 94 95 96 97

<u>disaggregated by gender, race, ethnicity, socioeconomic status,</u>	98
<u>and type of insurance coverage.</u>	99