February 20, 2023

HOUSE BILL No. 1201

DIGEST OF HB 1201 (Updated February 20, 2023 1:30 pm - DI 134)

Citations Affected: IC 16-18; IC 16-46.

Synopsis: Rare disease advisory council. Establishes the rare disease advisory council (council) to address various issues concerning the needs of patients in Indiana with rare diseases and their caregivers and providers. Establishes duties and procedures of the council. Requires the Indiana department of health to provide administrative assistance to and pay the administrative expenses of the council.

Effective: July 1, 2023.

Ledbetter, Bartels, Payne, Porter

January 10, 2023, read first time and referred to Committee on Public Health.
February 14, 2023, reported — Do Pass. Referred to Committee on Ways and Means pursuant to Rule 127.
February 20, 2023, amended, reported — Do Pass.

February 20, 2023

First Regular Session of the 123rd General Assembly (2023)

PRINTING CODE. Amendments: Whenever an existing statute (or a section of the Indiana Constitution) is being amended, the text of the existing provision will appear in this style type, additions will appear in **this style type**, and deletions will appear in ~~this style type.~~

Additions: Whenever a new statutory provision is being enacted (or a new constitutional provision adopted), the text of the new provision will appear in **this style type**. Also, the word **NEW** will appear in that style type in the introductory clause of each SECTION that adds a new provision to the Indiana Code or the Indiana Constitution.

Conflict reconciliation: Text in a statute in *this style type* or ~~*this style type*~~ reconciles conflicts between statutes enacted by the 2022 Regular Session of the General Assembly.

HOUSE BILL No. 1201

A BILL FOR AN ACT to amend the Indiana Code concerning health.

Be it enacted by the General Assembly of the State of Indiana:

SECTION 1. IC 16-18-2-84, AS AMENDED BY P.L.141-2014, SECTION 1, IS AMENDED TO READ AS FOLLOWS [EFFECTIVE JULY 1, 2023]: Sec. 84. **(a)** "Council", for purposes of IC 16-46-6, refers to the interagency state council on black and minority health.

(b) "Council", for purposes of IC 16-46-17, refers to the rare disease advisory council.

SECTION 2. IC 16-46-17 IS ADDED TO THE INDIANA CODE AS A **NEW** CHAPTER TO READ AS FOLLOWS [EFFECTIVE JULY 1, 2023]:

Chapter 17. Rare Disease Advisory Council

Sec. 1. As used in this chapter, "council" refers to the rare disease advisory council established by section 2 of this chapter.

Sec. 2. The rare disease advisory council is established.

Sec. 3. The duties of the council include the following:

(1) Conduct public meetings to survey the needs of patients in Indiana with rare diseases and their caregivers and providers.

(2) Provide testimony, comments, and recommendations

concerning legislation and rules that impact the community in Indiana with rare diseases.

(3) After consulting with experts on rare diseases, develop policy recommendations to improve patient access to and the quality of:

(A) rare disease specialists;

(B) affordable and comprehensive health care coverage;

(C) relevant diagnostics;

(D) timely treatment; and

(E) other needed services for patients with rare diseases.

(4) Research and make recommendations to state agencies and insurers that provide services to persons with rare diseases on the impact of prior authorization, cost sharing, tiering, or other utilization management procedures on the provision of treatment and care for patients.

(5) Evaluate and make recommendations to improve Medicaid coverage of drugs for patients with rare diseases to improve coverage of diagnostics, and facilitate access to necessary health care providers with expertise in the treatment of rare diseases.

(6) Publish a list of existing, publicly accessible resources on research, diagnosis, treatment, and education relating to rare diseases on the state department's website.

(7) Evaluate the current status and funding of pediatric cancer research taking place in Indiana and how the research interacts with the landscape of pediatric cancer research done nationally.

(8) Study other issues and provide grants that impact patients with rare diseases.

Sec. 4. (a) Beginning July 1, 2026, a chairperson shall be elected by the council members at the first meeting after July 1 every even-numbered year. If a vacancy occurs in the position of a member who is the chairperson, the council shall elect a member to serve the remainder of the chairperson's term at the next meeting of the council.

(b) The chairperson may not be a state employee.

(c) Before August 1, 2023, the governor shall appoint the chairperson of the council.

(d) The chairperson must meet one (1) of the qualifications of a member under section 5(b) of this chapter. This subsection expires July 1, 2026.

Sec. 5. (a) The following individuals serve as ex officio voting

members of the council:

(1) The director of the office of Medicaid policy and planning or the director's designee.

(2) The commissioner of the department of insurance or the commissioner's designee.

(3) The chief operating officer of the Indiana Minority Health Coalition or the officer's designee.

(b) Before September 1, 2023, the governor shall appoint the following voting members:

(1) A representative from a research university in Indiana that receives grant funding for rare disease research.

(2) A registered nurse or advanced practice registered nurse licensed under IC 25-23 with experience treating rare diseases.

(3) A physician licensed under IC 25-22.5 with experience treating rare diseases.

(4) A hospital administrator from a hospital licensed under IC 16-21 that provides care to individuals diagnosed with a rare disease.

(5) Two (2) patients who have a rare disease.

(6) A caregiver of an individual with a rare disease.

(7) A representative of a rare disease patient organization that operates in Indiana.

(8) A pharmacist with experience dispensing drugs used to treat rare diseases.

(9) A representative of the biopharmaceutical industry.

(10) A representative of a health carrier as defined by IC 27-1-46-3.

(11) A member of the scientific community who is engaged in rare disease research, which may include a medical researcher with experience conducting research on rare diseases.

Sec. 6. (a) The term of a member appointed to the council is three (3) years.

(b) Terms for appointed members begin on July 1 and end on June 30.

(c) An appointed member may not serve more than one (1) complete term.

(d) Notwithstanding subsection (a), the initial terms of the appointed members of the council under section 5 of this chapter are as follows:

(1) Members appointed under section 5(b)(1), 5(b)(4), 5(b)(7),

and 5(b)(10) of this chapter, for a term of two (2) years.

(2) Members appointed under section 5(b)(2), 5(b)(5), 5(b)(8), and 5(b)(11) of this chapter, for a term of three (3) years.

(3) Members appointed under section 5(b)(3), 5(b)(6), and 5(b)(9) of this chapter, for a term of four (4) years.

Sec. 7. A member of the council, may be removed by the governor for cause.

Sec. 8. If a vacancy occurs on the council, the governor shall appoint a qualified individual to serve the remainder of the term within sixty (60) days of receiving notice of the vacancy.

Sec. 9. (a) The council must conduct a meeting before October 1, 2023.

(b) Between September 1, 2023, and September 1, 2024, the council must meet not less than monthly.

(c) After September 1, 2024, the council must meet not less than quarterly.

(d) Any meeting of the council that uses electronic communications must comply with the requirements under IC 5-14-1.5.

Sec. 10. Eight (8) members of the council constitute a quorum. The affirmative vote of a majority of the quorum is required for the council to take any action.

Sec. 11. (a) Each member of the council who is not a state employee is entitled to receive both of the following:

(1) The minimum salary per diem provided by IC 4-10-11-2.1(b).

(2) Reimbursement for travel expenses and other expenses actually incurred in connection with the member's duties, as provided in the state travel policies and procedures established by the Indiana department of administration and approved by the budget agency.

(b) Each member of the council who is a state employee is entitled to reimbursement for travel expenses and other expenses actually incurred in connection with the member's duties, as provided in the state travel policies and procedures established by the Indiana department of administration and approved by the budget agency.

Sec. 12. The state department shall provide administrative assistance to and pay the administrative expenses of the council.

Sec. 13. (a) Beginning January 1, 2024, the council shall submit an annual report to the governor and the legislative council not later than June 15. The report submitted to the legislative council

must be in an electronic format under IC 5-14-6.

(b) The report required in subsection (a) must include the following:

(1) A summary of the council's activities and progress.

(2) Recommendations of the council to the governor and the general assembly on ways to address the needs of people living with rare diseases.

COMMITTEE REPORT

Mr. Speaker: Your Committee on Public Health, to which was referred House Bill 1201, has had the same under consideration and begs leave to report the same back to the House with the recommendation that said bill do pass.

(Reference is to HB 1201 as introduced.)

BARRETT

Committee Vote: Yeas 12, Nays 0

COMMITTEE REPORT

Mr. Speaker: Your Committee on Ways and Means, to which was referred House Bill 1201, has had the same under consideration and begs leave to report the same back to the House with the recommendation that said bill be amended as follows:

Page 2, between lines 23 and 24, begin a new line block indented and insert:

"**(7) Evaluate the current status and funding of pediatric cancer research taking place in Indiana and how the research interacts with the landscape of pediatric cancer research done nationally.**".

Page 2, line 24, delete "(7)" and insert "**(8)**".

Page 5, delete lines 1 through 3.

Page 5, line 4, delete "(3)" and insert "**(2)**".

Page 5, delete lines 7 through 18.

and when so amended that said bill do pass.

(Reference is to HB 1201 as printed February 14, 2023.)

THOMPSON

Committee Vote: yeas 18, nays 0.