

SENATE BILL No. 43

DIGEST OF INTRODUCED BILL

Citations Affected: IC 16-46-17.

Synopsis: Rare disease advisory council. Adds a physician member to the rare disease advisory council who specializes in the treatment of children with rare diseases. Adjusts the number of members required to establish a quorum.

Effective: July 1, 2024.

Breaux

January 8, 2024, read first time and referred to Committee on Health and Provider Services.



Second Regular Session of the 123rd General Assembly (2024)

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 2023 Regular Session of the General Assembly.

SENATE BILL No. 43

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

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

- 1 SECTION 1. IC 16-46-17-5, AS ADDED BY P.L.129-2023,
- 2 SECTION 2, IS AMENDED TO READ AS FOLLOWS [EFFECTIVE
- 3 JULY 1, 2024]: Sec. 5. (a) The following individuals serve as ex officio
- 4 voting members of the council:
- 5 (1) The director of the office of Medicaid policy and planning or
- 6 the director's designee.
- 7 (2) The commissioner of the department of insurance or the
- 8 commissioner's designee.
- 9 (3) The chief operating officer of the Indiana Minority Health
- 10 Coalition or the officer's designee.
- 11 (b) ~~Before September 1, 2023,~~ The governor shall appoint the
- 12 following voting members:
- 13 (1) A representative from a research university in Indiana that
- 14 receives grant funding for rare disease research.
- 15 (2) A registered nurse or advanced practice registered nurse
- 16 licensed under IC 25-23 with experience treating rare diseases.
- 17 (3) ~~A physician~~ **Two (2) physicians** licensed under IC 25-22.5



- 1 with experience treating rare diseases, **with at least one (1) who**
2 **specializes in the treatment of children with rare diseases.**
3 (4) A hospital administrator from a hospital licensed under
4 IC 16-21 that provides care to individuals diagnosed with a rare
5 disease.
6 (5) Two (2) patients who have a rare disease.
7 (6) A caregiver of an individual with a rare disease.
8 (7) A representative of a rare disease patient organization that
9 operates in Indiana.
10 (8) A pharmacist with experience dispensing drugs used to treat
11 rare diseases.
12 (9) A representative of the biopharmaceutical industry.
13 (10) A representative of a health carrier as defined by
14 IC 27-1-46-3.
15 (11) A member of the scientific community who is engaged in
16 rare disease research, which may include a medical researcher
17 with experience conducting research on rare diseases.
18 SECTION 2. IC 16-46-17-10, AS ADDED BY P.L.129-2023,
19 SECTION 2, IS AMENDED TO READ AS FOLLOWS [EFFECTIVE
20 JULY 1, 2024]: Sec. 10. ~~Eight (8)~~ **Nine (9)** members of the council
21 constitute a quorum. The affirmative vote of a majority of the quorum
22 is required for the council to take any action.

