

# PROPOSED AMENDMENT

## HB 1260 # 2

### DIGEST

Rare disease advisory council. Adds the state health commissioner of the Indiana department of health or the commissioner's designee as a member of the rare disease advisory council. Adjusts the number of members required to establish a quorum.

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- 1           Page 14, between lines 3 and 4, begin a new paragraph and insert:  
2           "SECTION 20. IC 16-46-17-5, AS ADDED BY P.L.129-2023,  
3           SECTION 2, IS AMENDED TO READ AS FOLLOWS [EFFECTIVE  
4           JULY 1, 2024]: Sec. 5. (a) The following individuals serve as ex officio  
5           voting members of the council:  
6                 (1) The director of the office of Medicaid policy and planning or  
7                 the director's designee.  
8                 (2) The commissioner of the department of insurance or the  
9                 commissioner's designee.  
10                (3) The chief operating officer of the Indiana Minority Health  
11                Coalition or the officer's designee.  
12                **(4) The state health commissioner or the commissioner's**  
13                **designee.**  
14           (b) Before September 1, 2023, the governor shall appoint the  
15           following voting members:  
16                 (1) A representative from a research university in Indiana that  
17                 receives grant funding for rare disease research.  
18                 (2) A registered nurse or advanced practice registered nurse  
19                 licensed under IC 25-23 with experience treating rare diseases.  
20                 (3) A physician licensed under IC 25-22.5 with experience  
21                 treating rare diseases.  
22                 (4) A hospital administrator from a hospital licensed under  
23                 IC 16-21 that provides care to individuals diagnosed with a rare  
24                 disease.  
25                 (5) Two (2) patients who have a rare disease.  
26                 (6) A caregiver of an individual with a rare disease.

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

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

5 (9) A representative of the biopharmaceutical industry.

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

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

11 SECTION 21. IC 16-46-17-10, AS ADDED BY P.L.129-2023,  
12 SECTION 2, IS AMENDED TO READ AS FOLLOWS [EFFECTIVE  
13 JULY 1, 2024]: Sec. 10. ~~Eight (8)~~ **Nine (9)** members of the council  
14 constitute a quorum. The affirmative vote of a majority of the quorum  
15 is required for the council to take any action."

16 Renumber all SECTIONS consecutively.  
(Reference is to HB 1260 as introduced.)