

Rare Disease Advisory Council

Bylaws

Revision as of February 9, 2024

Article I: Name

The Rare Disease Advisory Council (Council) was established through Indiana Code 16-46-17-2.

Article II: Purpose

The purpose of the of the Council is to make recommendations to the General Assembly on ways to address the needs of Hoosiers living with rare diseases. A summary of the Council's activities, progress and recommendations are due annually no later than June 15.

Article III: Membership

1. Prior to July 1, 2026, the governor shall appoint the chairperson.
2. Beginning July 1, 2026, and then after July 1 of every even numbered year, the Council shall elect their chairperson.
3. Members may only fill one stated category.
4. Members shall include the following ex officio voting members:
 - a. Director of the office Medicaid policy and planning or director's designee.
 - b. Commissioner of the department of insurance or commissioner's designee.
 - c. Chief operating officer of the Indiana Minority Health Coalition or the officer's designee.
5. Other members include:
 - a. A representative from a research university in Indiana that receives grant funding for rare disease research.
 - b. A registered nurse or advanced practice registered nurse licensed under IC 25-23 with experience treating rare diseases.
 - c. A physician licensed under IC 25-22.5 with experience treating rare diseases.
 - d. A hospital administrator from a hospital licensed under IC 16-21 that provides care to individuals diagnosed with a rare disease.
 - e. Two (2) patients who have a rare disease.

- f. A caregiver of an individual with a rare disease.
 - g. A representative of a rare disease patient organization that operates in Indiana.
 - h. A pharmacist with experience dispensing drugs used to treat rare diseases.
 - i. A representative of the biopharmaceutical industry.
 - j. A representative of a health carrier as defined by IC 27-1-46-3.
 - k. 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.
6. The term for membership follows all requirements of IC 16-46-17-6.
7. Members may be removed by the governor for cause and vacancies will be filled by the governor's office within sixty (60) days of receiving notification from the Council Chairperson.

Article IV: Duties

- 1) In accordance with IC 16-46-17-3, the Council shall engage in the following activities:
- a. Conduct public meetings to survey the needs of the patients with rare diseases and their caregivers and providers.
 - b. Provide testimony, comments, and recommendations concerning legislation and rules that impact the patients in Indiana with rare diseases.
 - c. After consulting with experts on rare diseases, develop policy recommendations to improve patient access to and the quality of:
 - 1) rare disease specialists;
 - 2) affordable and comprehensive health care coverage;
 - 3) relevant diagnostics;
 - 4) timely treatment; and
 - 5) other needed services for patients with rare diseases.
 - 6) 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.
 - 7) 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.

- 8) Publish a list of existing, publicly accessible resources on research, diagnosis, treatment, and education relating to rare diseases on the state department's website.
 - 9) 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.
 - 10) Study other issues and provide grants that impact patients with rare diseases.
- 2) When appropriate, the Rare Disease Committee will select a member to serve on its behalf on the Perinatal Genetics and Genomic Advisory Committee. This member shall provide regular updates to the Rare Disease Advisory Committee about activities on the Perinatal Genetics and Genomic Advisory Committee.
 - 3) If the chairperson is unable to fulfill their role, the chairperson may appoint a substitute chair from existing RDAC membership. For substitutions that last longer than six (6) meetings, another chairperson appointment shall be solicited from the Office of the Governor.

Article V: Voting

1. RDAC Attendance Guidelines and Electronic Communications Meeting Policy attached and included in voting policies.
2. Eight members constitute a quorum. The affirmative vote of a majority of the quorum is required for the council to take any action.
3. Proxies sent on behalf of appointed members are given the ability to vote in lieu of appointed members.
4. Decisions approved through vote by the RDAC will stand unless another vote is taken to change them.

Article VI: Forfeiture of Membership

A member may forfeit membership for failure to act ethically, failure to fulfill responsibilities outlined in these bylaws or due to change in job title, job functions, or employer affiliation.

Article VII: Meetings

1. All meetings will comply with IC 16-46-17.
2. Between September 1, 2023, and September 1, 2024, the council will meet monthly.
3. After September 1, 2024, the council will meet at least quarterly.

4. Public notice of the date, time, and place of any meetings, executive sessions, or of any rescheduled or reconvened meeting, shall be given at least forty-eight (48) hours (excluding Saturdays, Sundays, and legal holidays) before the meeting.
5. Committee meetings will be publicly announced in accordance with the Indiana Department of Health Policies and Procedures.
6. Committee meeting between members which constitute a quorum will be publicly announced in according to the Indiana Department of Health policies and procedures.

Article VIII: Effective Date

The effective date of these bylaws is February 9, 2024.