

Perinatal Genetics & Genomics Advisory Committee

Bylaws

Effective Date: August 27, 2024

ARTICLE I. AUTHORITY

The Perinatal Genetics and Genomics Advisory Committee was formed under Indiana Code (IC) 16-41-17-2 during the 2022 Indiana General Assembly, thus the Perinatal Genetics and Genomics Advisory Committee is mandated to follow the obligations of Indiana's Open Door Law. The amendments to IC 16-41-17-2 permit the committee to recommend conditions to be added or deleted from the mandated newborn screening panel for Indiana.

ARTICLE II. PURPOSE

The purpose of these bylaws is to establish operational guidelines for the conduct of business of the Perinatal Genetics and Genomics Advisory Committee, herein referred to as "PGGAC" or "the Committee."

ARTICLE III. MEMBERSHIP

The membership of the PGGAC shall consist of up to 17 members. Members shall be experts in newborn screening, including: (1) Medical, public health, or scientific professionals with special expertise in the field of heritable disorders or in providing counseling, testing, or specialty services for newborns and children at risk for heritable disorders; (2) Laboratory professionals with expertise in newborn screening methodologies; (3) Individuals with expertise in ethics; and/or (4) Individuals with expertise in infectious disease who have worked and published materials in the area of newborn screening. Members shall be appointed by the Indiana Department of Health (IDOH). IDOH will ensure that the total membership of the committee is an odd number for voting purposes. Members will serve for a two-year term and may be reappointed for additional terms. Membership shall include geneticists, genetic counselors, laboratory staff, pediatric specialists, pediatricians, family physicians, neonatologists, and nurse practitioners practicing in metabolic clinics, medical ethicists, and other medical experts as the IDOH determines necessary.

ARTICLE IV. ROLES AND RESPONSIBILITIES

IDOH Staff will assist the committee in the following administrative ways:

1. Locating, organizing, and preparing pertinent background information.
2. Interpreting programmatic policies, regulations, and statutes.
3. Drafting reports and meeting minutes.
4. Making meeting arrangements.
5. Collaborating with the chairperson and vice-chairperson in establishing meeting agendas and approval of meeting minutes.



6. Writing reports for the review, revision, and approval of the chair, vice-chair, and membership regarding recommendations to IDOH.

Leadership: The IDOH shall appoint a chairperson and vice-chairperson who shall preside for a term of two (2) years. The chairperson shall have the responsibilities of regular members and the following additional responsibilities:

1. Ensuring all respective parties are represented.
2. Preside over meetings.
3. Approve meeting agendas.
4. Decide points of order.
5. Call for votes on issues.
6. Consult with vice-chair and IDOH in developing reports and recommendations.
7. Provide written recommendations from the Committee's formal votes to IDOH.

The vice-chairperson shall have the same responsibilities as regular members and will perform all the duties of the chairperson when that person is absent. The vice-chairperson shall serve as the chairperson when that position has been vacated until the membership is able to select a new chairperson.

PGGAC members shall:

1. Attend committee meetings in accordance with the attendance and electronic communication policy.
2. Review agenda items and the supporting documentation before meetings.
3. Provide input on ideas and participate in discussions.
4. Review and comment on research, reports, and other background information.
5. Recommend strategies or policy changes for improved and expanded condition detection and management.
6. Cast votes on issues requiring a vote if they are voting members.
7. Resign, in writing to IDOH, within thirty (30) days prior to their resignation date.

Members shall not participate in legislative activity in the name of the Committee or IDOH. Committee members may represent themselves or other entities in the legislative process.

Guest experts/speakers: The Committee may request guest experts and speakers should it be deemed necessary or in the Committee's best interest to hear from specific experts on the matter of official business. Guest experts/speakers may not vote on official actions of the Committee.

Membership will be reviewed within six (6) months of the end of every two-year cycle. Current members may be appointed for additional terms on the committee. If roles become vacant, IDOH staff will assist with recruiting and appointing appropriate members, in conjunction with the Chairperson.



ARTICLE V. MEETINGS

The Committee shall meet at least quarterly to discuss the addition or deletion of conditions to newborn screening. Additional meetings are at the discretion of the committee and the work being completed.

The Committee must have a simple majority of the voting membership to constitute a quorum at any meeting. The Committee may meet without a quorum but may not conduct votes on any official business.

A simple majority of the quorum voting in favor of the motion is needed for the motion to pass. Issues requiring a vote are those that would require significant change by the program, such as addition of a new disorder to the required screening panel or deletion of a current condition from the required screening panel. The Committee shall provide these changes as formal written advice to IDOH.

The Committee will designate a public comment period during each meeting lasting no longer than 20 minutes. Public comments may be made during meetings prior to official action by the Committee if a member of the public is present and provides their name and any organizational affiliation. It is preferred that public comments are submitted in writing via email to newbornscreening@health.in.gov one (1) business day prior to the meeting. Public comments will be prioritized based on the receipt of request for public comment.

While committee members are encouraged to attend all meetings in person, IC 5-14-1.5-3.6 authorizes some committee members to participate in meetings electronically. However, at minimum, one third (1/3) of the members must be physically present at the place where the meeting is conducted. Any electronic participation in meetings by committee members must comply with the committee's most recent electronic communication policy.

ARTICLE VI. SUBCOMMITTEES

The full Committee may propose the creation of subcommittees to carry out specific duties.

A subcommittee that:

- (1) Is appointed by the PGGAC;
- (2) Meets for the sole purpose of receiving information, deliberating, or making recommendations to the PGGAC; and
- (3) Does not have more than one (1) member of the PGGAC

is not subject to Open Door Laws. Any other subcommittee is subject to all the requirements of the Open Door Laws. Any subcommittee must report back to the full Committee.

ARTICLE VII. AMENDMENTS

These bylaws may be amended by the Committee at any meeting, by a two-thirds (2/3) vote of those voting, a quorum being present, provided at least ten (10) days' notice of the proposed amendment has been given to the membership in writing.

