

# **Pennsylvania Department of Health**

## **Newborn Screening and Follow-up Technical Advisory Board**

### **Bylaws**

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## **ARTICLE I-NAME**

This body shall be known as the Newborn Screening and Follow-up Technical Advisory Board (NSFTAB or Board) to the Department of Health (Department or DOH).

## **ARTICLE II-PURPOSE**

The purpose of this Board is to provide recommendations, guidance and support to the Department regarding the responsibility for the planning, evaluation, modification and management of the statewide Newborn Child Screening and Follow-up Program under the Newborn Child Testing Act (35 P.S. § 621, et. seq.) and to provide approval(s) in accordance with the requirements of the Newborn Child Testing Act.

## **ARTICLE III-MEMBERSHIP**

### **Section 1 Appointment**

The existing members of the Newborn Screening and Follow-up Technical Advisory Committee shall initially comprise the members of the Board. In the event of vacant positions on the Board, the Chairperson of the Board may call for nominations. The Board may evaluate and recommend potential candidates to the Secretary of Health for consideration. The Secretary shall make the final determination on all appointments and shall appoint members to the Board.

### **Section 2 Term**

All members shall serve for a term of two (2) years and may be re-appointed.

### **Section 3 Composition of Board Membership**

The Board shall, at a minimum, be composed of the named positions in accordance with the Newborn Child Testing Act - Newborn Child Screening And Follow-Up Program And Mandated Screening And Follow-Up Act of Nov. 25, 2020, P.L. , No. 133 (Act 133) and shall include:

- An ethicist;
- Three pediatric physicians;
- A neonatologist;
- A genetic counselor;
- A hematologist;
- Two clinical geneticists;
- A nurse midwife;
- A parent advocate, and;
- A representative recommended by the Hospital and Health System Association of Pennsylvania.

Additional positions may be included as determined by the Board, not to exceed a total of 15 Board members.

Each named position shall serve for a term(s) following the procedures in Article III, Section 2. Additional positions shall also serve for a term(s) as required to achieve the purpose for which the position is created following the procedures in Article III, Section 2. Members shall provide primary clinical and or professional services through a medical facility or organization located in Pennsylvania.

### **Section 4 Removal**

Board members who fail to meet attendance requirements, fail to disclose conflicts of interest, fail otherwise to comply with the Department's Code of Conduct, or fail to perform their duties in accordance with these bylaws may be forwarded to the Secretary with a recommendation that they be removed from the Board. Accompanying this recommendation will be suggested nominations to fill the individual's unexpired term.

### **Section 5 Compensation**

No member shall receive any compensation for performance of duties specified in, or arising out of his or her duties as a Board member. Members may receive necessary travel expenses.

### **Section 6 Authority**

The Newborn Screening and Follow-up Technical Advisory Board is organized as an advisory body to the Department of Health in the Commonwealth of Pennsylvania under the Newborn Child Testing Act (35 P.S. § 621, et. seq.). Board members do not have the authority to represent the Commonwealth or the Department of Health in any official capacity.

### **Section 7 Voting**

All Board members shall have voting rights. Voting shall not be held where a quorum is not present. Where a quorum is present, an affirmative vote of a majority of the Board membership constituting the quorum shall be required to pass or approve a measure. Tied vote(s) shall be decided by the Chairperson of the Board.

## **ARTICLE IV-DUTIES OF BOARD**

### **Section 1 Attendance**

It is anticipated that Board members will attend a minimum of two Board meetings each year in person. Meetings may also be held virtually if needed as determined by the Department. Board members shall respond to the meeting notice about their planned attendance or absence. Board members with an outstanding engagement can notify the Chairperson in advance to request an excused absence. The names of Board members missing more than two meetings a year may be forwarded to the Secretary with a recommendation that they be removed from the Board. Accompanying this recommendation will be suggested nominations to fill the individual's unexpired term.

### **Section 2 Participation**

Board members shall be prepared for meetings. Board members shall participate in voting on measures as requested by the Department and as required by the Newborn Child Testing Act.

### **Section 3 Code of Conduct**

Board members shall be responsible to follow the Code of Conduct appended to these by-laws. Board members shall notify the Department's legal counsel of any conflict with the Code of Conduct as soon as practicably possible and shall notify the Department's legal counsel of the member's recusal from any Board activity prior to the activity.

## **ARTICLE V-OFFICERS**

### **Section 1 Officers of Board**

The Board shall have two officers: Chairperson and Vice Chairperson.

### **Section 2 Nomination and Election of Officers**

At the Board meeting prior to the final meeting of the calendar year, the Board Chairperson shall call for nominations to fill the expiring officer position(s) on the Board. Nominated Board members do not need to be present at the time of nomination. The Newborn Screening and Genetics (NSG) Division Director or their appointee shall confirm the nominations by contacting each nominee to obtain their acceptance of the nomination and their intent to serve if elected. At the final Board meeting of the applicable calendar year, the Board shall conduct the election of Chairperson and/or Vice Chairperson from the slate of nominees from the prior meeting and as confirmed by the NSG Division Director. The slate of nominees shall be made known to the Board by mail or e-mail at least two weeks prior the last Board meeting of applicable each calendar year by the Department's NSFTAB Program Manager. Ballots may be cast prior to the meeting by mailing or e-mailing the ballot directly to the NSFTAB Program Manager. The NSG Division Director or their appointee shall conduct the election of officers at the meeting and shall be responsible for tallying the votes received. Officers must be elected by a majority of the current Board membership.

### **Section 3 Term of Officers**

The officer(s) shall take office after the adjournment of the election and serve for a period of two (2) years or for the duration of their tenure on the Board, whichever is shorter. The officer(s) may be re-elected. In the event the officer vacates his/her position before the end of his/her term, the Board shall hold a special election to fill the vacant position following the procedures in Article V, Section 2. The new officer shall serve for the remainder of the term of the vacated position, or for the duration of their tenure on the Board, whichever is shorter.

## **ARTICLE VI-DUTIES OF OFFICERS**

### **Section 1 Chairperson Duties**

The duties for the Chairperson shall include:

- Working with the NSFTAB to set the agenda for all meetings of the Board;
- Presiding at all meetings of the Board,
- Determining if a quorum exists at each meeting where a vote shall be held,
- Calling for votes as necessary and as otherwise described in these bylaws,
- Coordinating the process for nomination of individuals to the Board, and
- Carrying out other duties as may be assigned by the Board within these bylaws.

### **Section 2 Vice Chairperson Duties**

The duties of the Vice Chair shall include:

- Assuming the Chairperson's duties during vacancy in the office of the Chairperson,
- Performance of the Chairperson's duties when the Chairperson is unable to perform his/her duties, and
- Carrying out other duties as may be assigned by the Board within these bylaws.

### **Section 3 Board Member Duties**

The duties of Board members shall include, but not be limited to the following:

- Become familiar with the Commonwealth's newborn screening law and regulations;
- Become familiar with the newborn screening and follow-up program structure, budget and operations;
- Review newborn screening and follow-up policies, procedures, treatment standards, and laboratory methods;
- Review newborn screening data and trends for all conditions screened under Pennsylvania law;
- Provide recommendations for setting policy and other guidance for the newborn screening and follow-up program;
- Become familiar with the activities of the national Advisory Committee on Heritable Disorders in Newborns;
- Assist the newborn screening and follow-up program in setting program priorities, educational plans and programs; and
- Assist the newborn screening and follow-up program in the exchange of information between community stakeholders and the Department.

## **ARTICLE VII-MEETINGS**

### **Section 1 Frequency**

The Board shall meet at least three times annually. The Chairperson, in coordination with the NSG Division Director, may call additional meetings as necessary to meet the needs of the Board, with the approval of the Department. The NSFTAB Program Manager shall provide Board members with a written notice as far in advance of the meeting as possible. In general, at least four (4) weeks notice should be given prior to a meeting. The Department shall be responsible for taking meeting minutes at Board meetings.

## **Section 2 Quorum**

A majority of voting Board members must be in attendance in person or via teleconference to constitute a quorum. A quorum shall consist of a majority of the current NSFTAB membership.

# **ARTICLE VIII-SUB-COMMITTEES**

## **Section 1 Sub-committee Chair**

The Board Chairperson shall appoint a Sub-committee Chair for each sub-committee. The Sub-committee Chair must be a member of the NSFTAB. The Sub-committee Chair will serve for a term required for the sub-committee to achieve the purpose for which the sub-committee was created, or for the duration of his or her tenure on the NSFTAB, whichever is shorter. The duties of the Sub-committee Chair shall be to direct the activities of the sub-committee to achieve the purpose for which the sub-committee was created and other duties assigned by the Board Chairperson.

## **Section 2 Sub-committee Membership**

The Board Chairperson, after the creation of sub-committees by the Board, shall call for volunteers for each sub-committee from the Board members. Once appointed by the Board Chairperson, the Sub-committee Chair shall request non-NSFTAB members with clinical and/or professional expertise to join the subcommittee on an as needed basis. Other non-NSFTAB subject matter experts shall be invited to join the sub-committee by the Sub-committee Chair by request only. Sub-committee members shall serve for the time required for the sub-committee to achieve the purpose for which it was created, or for the duration of their tenure on the NSFTAB if they are NSFTAB members, whichever is shorter. Sub-committee members may be removed from their service on a sub-committee by the NSFTAB Chairperson or the NSG Division Director, each in their sole discretion.

All sub-committee members shall disclose all conflicts of interest before participating in sub-committee meetings by completing the Conflict of Interest Form provided by the Program. The Board Chairperson, or Vice Chairperson will determine if a conflict exists. Subcommittee members with an actual conflict may remain on the committee and participate in the discussion to lend expertise but will be expected to recuse themselves and abstain from voting. All Board members participating in sub-committees are not required to sign a second or additional Conflict of Interest Forms.

## **Section 3 Sub-committee Meetings**

The Board Chairperson and/or the Sub-committee Chairperson may call a sub-committee meeting/conference call between Board meetings or at any Board meeting, with the approval of the Department. If the Sub-committee Chairperson is not available, the Sub-committee Chairperson is responsible for appointing another Sub-committee member to conduct the sub-committee meeting. The Sub-committee Chairperson shall submit minutes of the sub-committee meeting/conference calls to the NSFTAB Program Manager no later than fourteen (14) days after such meeting.

## **Section 4 Compensation**

No sub-committee member shall receive compensation for performance of duties specified in, or arising out of his or her duties as a Board and/or sub-committee member. Sub-committee members shall receive necessary travel expenses.

# **ARTICLE IX-AMENDMENTS**

These bylaws may be amended, at any meeting where a quorum exists, by majority vote of the full (active) Board. Votes may be cast in advance by mail or e-mail. Proposed amendments to the bylaws shall be submitted to the Board Chairperson at least three (3) weeks before the meeting where the proposed amendment is scheduled to be presented. Bylaw changes will be in effect at the meeting immediately following an affirmative vote on the revisions in accordance with this Article.

# **ARTICLE X-PARLIAMENTARY AUTHORITY**

Robert's Rules of Order, Newly Revised shall prevail in all cases in which they are applicable and are not in conflict with these bylaws, the Newborn Child Testing Act, or any other provision of Pennsylvania law or Department or Commonwealth policy.

**Newborn Screening and Follow-up Technical Advisory Board**  
**Bylaws Adopted on March 28, 2024.**

**Chair:**

Laurie Varlotta, MD  
**Signature**

Laurie Varlotta, MD  
**Name**

**Vice Chair:**

\_\_\_\_\_  
**Signature**

\_\_\_\_\_  
**Name**