

Newborn Screening Advisory Committee

Bylaws

1. Name and Legal Authority

The Newborn Screening Advisory Committee is established in accordance with Texas Health and Safety Code § 33.017 and Title 25, Texas Administrative Code §37.64. This Committee is not subject to Texas Government Code Chapter 2110 (State Agency Advisory Committees).

2. Purpose and Role

The purpose and tasks of the Committee are to advise the Texas Department of State Health Services (DSHS) on matters as described below:

- A. Advise DSHS regarding strategic planning, policy, rules, and services related to newborn screening, and additional newborn screening tests; and
- B. Review the necessity of requiring additional screening tests, including an assessment of the test implementation costs to the department, birthing facilities, and other health care providers.

The Committee may advise DSHS by submitting recommendations to the DSHS Commissioner at any time via letter format.

3. Definitions

Committee - Newborn Screening Advisory Committee

Conflict of interest - A situation in which a member has a personal or private interest where they could benefit from actions or decisions made in their official capacity.

DSHS - Texas Department of State Health Services

HHSC - Texas Health and Human Services Commission

HHS - Health and Human Services

High Level of Integrity - For purposes of these Bylaws, this means that the member is honest and behaves in a morally upright way, at a level above a normal or average level, such that the public's trust in the member is warranted. A high level of integrity includes disclosing conflicts of interest as required by HHS policy and these Bylaws.

NBS - Newborn Screening Program

Personal or private interest - An interest that does not include the member's engagement in a profession, trade, or occupation when the member's interest is the same as all others similarly engaged in the profession, trade, or occupation, or if the member merely provides a personal experience, with no personal or private financial interest, in giving feedback on the subject matter.

TAC - Texas Administrative Code

4. Committee Composition

The Committee is composed of at least 10 voting members as described in Texas Health & Safety Code § 33.017. The DSHS Commissioner added three members for a total of 13 voting members. All members must be appointed by the DSHS Commissioner.

This membership includes:

- A. At least four physicians licensed to practice medicine in Texas, including at least two physicians specializing in neonatal-perinatal medicine;
- B. At least two hospital representatives;
- C. At least two people who have family members affected by a condition for which newborn screening is or may be required under Texas Health & Safety Code, Chapter 33, Subchapter B;
- D. At least two health care providers who are involved in the delivery of newborn screening services, follow-up, or treatment in Texas;
- E. One person with sickle cell disease or trait, or a person who has a family member with sickle cell disease or trait; and
- F. One health care provider who is involved in the delivery of newborn screening services, follow-up, or treatment of sickle cell disease or trait in Texas.

Under HHS Policy and to the greatest extent possible, the DSHS Commissioner appoints members who reflect the diversity of Texas.

5. Member Terms

All members serve a term of three years, except when appointed to complete the remaining unexpired term of an outgoing member. Members may apply for reappointment to serve one additional term and may serve these terms

consecutively. Members who begin their first term after August 31, 2022 may serve a maximum of two terms.

Bylaws prior to July 2018 did not restrict term limits. Bylaws were amended allowing members appointed or reappointed after July 2018 and before August 31, 2022 to serve a maximum of three terms. However, member terms completed prior to July 2018 are not counted toward term limits. Members who began their first term prior to August 31, 2022, may serve a maximum of three terms. Initial terms were staggered over several years to support continuity of Committee work so that the terms of one-third of the members expire each year. With the adoption of these Bylaws, member terms will expire on August 31st of each year.

Regardless of the term limit, a member serves until his or her replacement has been appointed. This allows sufficient, appropriate representation.

6. Resignations and Vacancies

If any member of the Committee wishes to resign, the member will contact, in writing, the current Chair and DSHS Committee Liaison requesting the appointment of a successor member.

In the event of a vacancy for any reason, agency staff will work with the DSHS Commissioner to solicit applications as appropriate to fill the vacancy with a representative of the same membership category to serve the unexpired portion of the term of the vacant position. People who submitted applications within the previous year but were not selected through DSHS may be reconsidered for membership.

7. Presiding Chair and Vice-Chair

The Committee shall elect a Chair, and a Vice-Chair to serve in the Chair's temporary absence, from its members who shall preside over each Committee meeting. The Chair and Vice-Chair will serve one term of two years. A Chair or Vice-Chair may serve no more than one term in that office and may serve one term in the other office, if elected. In the event that either officer is unable to complete his or her term for any reason, a new officer will be elected. Regardless of the expiration of the term, the Chair and Vice-Chair will serve until the Committee elects a successor; however, a presiding officer may not remain in office past his or her appointment to the Committee.

The role of the Chair and Vice-Chair is to:

- A. Report to DSHS;
- B. Participate in agenda planning and preparation for committee meetings;
- C. Provide leadership in conducting Committee meetings
- D. Promote, maintain, and encourage a participatory environment;
- E. Identify the need for, and work with Committee Liaison, to call meetings in accordance with Health and Safety Code, § 33.017, to accomplish the work of the Committee;
- F. Ensure the Committee adheres to its charge;
- G. Serve as an ex-officio member of any subcommittee of the Committee;
- H. Call for the establishment of subcommittees (if appropriate and with approval of agency staff); and
- I. Confer with DSHS staff to acquire the support needed for Committee operations.

8. Committee Operations and Meetings

A. Meetings

- 1. The Committee meets during regular business hours, at the call of the Chair or DSHS commissioner, at least three times a year.
- 2. The Committee announces and conducts its meetings in accordance with Texas Government Code Chapter 551 (the Texas Open Meetings Act) as if it were a governmental body.

B. Quorum

A majority of members constitutes a quorum for the purpose of transacting official business. To calculate a majority for a committee with an odd number of members, divide the membership by two and round up to the next whole number. If less than a quorum of the Committee is present, members may not vote upon action items but may take testimony and public comments so long as the meeting is being conducted in accordance with the Texas Open Meetings Act.

C. Voting

- 1. Members have the right to vote on any subject listed on the agenda. However, members must abstain from deliberating or voting on issues that would provide monetary or other gain to the member, or the member's family, or that could present, or reasonably appear to present, a conflict of interest.
- 2. The Committee may determine procedural matters by majority vote of members attending the meeting or may use Robert's Rules of Order as a guide to its operations and proceedings.
- 3. A member may participate and vote in person or by video conference call as deemed necessary by agency staff.

4. A member may not authorize another person to represent the member by proxy.
5. For all business except adopting or amending Bylaws, a simple majority is needed on a motion duly made and seconded. (A simple majority is defined as more than half of the votes cast by persons entitled to vote who are in attendance with a quorum, excluding abstentions.)

D. Adoption and Revision to Bylaws

1. Bylaws will be adopted and amended pursuant to a two-thirds vote (of members attending the meeting) on a motion duly made and seconded.
2. Committee members or DSHS staff may propose changes to these Bylaws. All proposed changes from Committee members, along with the rationale for the changes, should be submitted in writing to the DSHS Committee Liaison at least 30 days prior to the next committee meeting. The DSHS Committee Liaison will ensure an item for Bylaws discussion is included on the agenda to be posted on the Secretary of State's Open Meetings website. Proposed changes to the Bylaws must be distributed to the members before the meeting for their consideration.
3. The Committee will review the Bylaws by December 31 of every even-numbered year. Committee-proposed amendments that occur as a result of the biennial review will be considered in a meeting and will be passed and become effective based on a two-thirds vote of members attending the meeting, pending review and approval by DSHS and HHSC staff.
4. All proposed changes are subject to review and approval by DSHS and HHSC staff.
5. The Bylaws will become effective as of the date they are adopted or amended by the Committee. The Committee will make note of the date of the adoption or amendment of the Bylaws in its minutes. Members will sign the Statement by Members when Bylaws are adopted or amended (see attached Statement).

9. Responsibilities of Members

A. Attendance

Members are expected to attend all meetings. Members can attend in person or by videoconference call. A member unable to attend a meeting should notify the Committee Liaison in advance. The Committee Liaison will notify the Chair and appropriate program staff. Members may not send a substitute to attend a meeting in their place.

Any member missing three meetings within a one-year period with or without notice to the Committee Liaison, may be removed from the Committee.

B. Member expectations:

1. Attend meetings in person or by video conference call;
2. Participate in subcommittees as assigned;
3. Review agendas and other information sent by staff prior to each meeting;
4. Participate in discussions at meetings;
5. Abstain from deliberating or voting on issues that would provide monetary or other gain to the member, or the member's family, or that could present, or reasonably appear to present, a conflict of interest;
6. Attend/participate in an orientation session for the Committee;
7. Complete the Texas Open Meetings Act Training and Public Information Act Training within 90 days of appointment and submit the Certificates of Completion to the Committee Liaison. A member who has taken the trainings within the last five years may submit a copy of the Certificates of Completion to the Committee Liaison in lieu of retaking the trainings;
8. Sign and submit to the Committee Liaison the Statement by Members document (attached) within 30 days after appointment. This document includes a Conflict of Interest Statement and a Nondisclosure Agreement to which Committee members must agree;
9. Notify the Committee Chair and Committee Liaison if a change of status alters the category of membership that the member was filling or if any circumstance occurs that prevents the member from being able to discharge his or her duties;
10. Maintain a high level of integrity that warrants public trust, including complying with all applicable ethics guidance provided by HHS's Ethics Officers and all aspects of the Texas Open Meetings Act and Public Information Act; and
11. Hold and maintain in strictest confidence all confidential information and all agency-generated information, including information in draft form, until such time as the information or document is released and made public, the DSHS Commissioner or HHS Executive Commissioner has approved the release in writing, or the HHS Ethics Policy permits release. This requirement survives the member's tenure on the Committee. In addition, the member must confirm that he or she will require the member's interpreters, attendants, or other support persons, if any, to comply with this requirement. For purposes of these Bylaws and the Nondisclosure Agreement, the term "confidential information" includes all information protected by the Health Insurance Portability and Accountability Act (HIPAA), information that has commercial value or use, such as trade secrets, and information communicated in confidence by the HHS System.

Failure to comply with member expectations numbers 5-11 above are grounds for dismissal and may result in removal from the Committee.

C. A Committee member may not:

1. Claim or appear to represent HHSC, DSHS or the Committee in any legislative or advocacy activity without written approval from the Committee Chair and the HHS Ethics Office in coordination with the HHS Government and Stakeholder Relations Office and the Committee Liaison. A member is not prohibited from discussing a report that has been formally adopted by this Committee, so long as he or she does not purport to represent HHSC or DSHS. A member is not prohibited from representing him- or herself or another entity in the legislative or advocacy process.
2. Accept payment for any services offered to the member because of his or her position on the Committee.
3. Disclose confidential information or draft information (from any source including grants, requests for proposals, and contracts) acquired through his or her participation on the Committee until such time as that information or document is released and made public, the DSHS Commissioner or HHS Executive Commissioner has approved the release in writing, or the HHS Ethics Office permits release. Members cannot disclose information using any form of communication including written, digital, verbal, and social media.
4. Fail to require the member's interpreters, attendants or other support persons, if any, to keep confidential information or draft information (from any source including grants, requests for proposals, and contracts) acquired through the member's participation on the Committee until such time as that information or document is released and made public, the DSHS Commissioner or HHS Executive Commissioner has approved the release in writing, or the HHS Ethics Policy permits release. This includes all forms of communication including written, verbal, and social media.

A violation of any of these items is grounds for dismissal and may result in removal from the Committee.

10. Removal from the Committee

The DSHS Commissioner may remove a member from the Committee, or may request the appointing agency to designate a new individual, for the following reasons:

- A. A member votes or deliberates on an issue that would provide monetary or other gain or that presents a conflict of interest to the member, the member's family, or an entity with which the member is closely affiliated.
- B. A member refuses to sign or violates the Statement by Members, which includes the Conflict of Interest statement and Nondisclosure Agreement, or another Nondisclosure Agreement.
- C. A member does not maintain a high level of integrity that warrants public trust, including complying with all applicable ethics guidance provided by HHSC's Ethics Officers and all aspects of the Texas Open Meetings Act and Public Information Act.
- D. A member changes status that alters the category of membership that the member was filling.
- E. A member claims or appears to represent HHSC, DSHS or the Committee in a legislative or advocacy activity without approval from the Committee chair and the HHS Ethics Office in coordination with the HHS Government and Stakeholder Relations Office and Committee Liaison. (A member is not prohibited from discussing a report that has been formally adopted by this Committee, so long as he or she does not purport to represent HHSC or DSHS. A member is not prohibited from representing him or herself or another entity in the legislative or advocacy process.)
- F. A member receives payment for any services requested because he or she holds a position on the Committee.
- G. A member discloses confidential, including draft information, acquired through his or her participation on the Committee not in accordance with the Bylaws.
- H. A member fails to require his or her interpreter, attendant or other support person, if any, to keep confidential any information or draft information acquired through the member's participation on the Committee as required by the Bylaws.
- I. A member, in a 12-month period, misses three or more meetings with or without notice to DSHS staff.

Decisions to remove a member of the Committee due to violations of this nature will require input from HHS legal counsel.

11. Subcommittees

Unless otherwise noted in statute, the Chair, with the approval of agency staff, may establish subcommittees that meet at other times for purposes of studying and making recommendations on issues the Committee determines appropriate to the purpose and tasks of the Committee. A subcommittee may be created for a limited period of time and will cease to exist when the assigned tasks are completed or

upon determination of the Chair or DSHS Commissioner, or it may be a standing subcommittee. The Chair and agency staff will evaluate the need for all existing subcommittees annually.

Subcommittee Operations and Meetings

- A. Unless otherwise noted in statute or required by a grant document, members of subcommittees are required to be members of the Committee.
- B. Except as set out in #D below, subcommittee(s) will follow the general rules of the Committee as applicable.
- C. Subcommittee(s) must keep minutes of the meetings and report back to the full body.
- D. The presence of a quorum of the full Committee at a subcommittee meeting:
 1. Constitutes a full Committee meeting that requires posting appropriate notice of the meeting as a full Committee meeting in accordance with DSHS policy and the Texas Open Meetings Act; and
 2. Requires the subcommittee meeting to be held in compliance with DSHS policy and the Texas Open Meetings Act to include posting appropriate notice of the subcommittee meeting.

12. Subject Matter Experts

DSHS recognizes the value of subject matter experts (SMEs) to provide information to the Committee as it develops recommendations and initiatives relative to its purpose and task(s). The primary role of a SME is to provide objective, independent information and analysis to be considered by the Committee. SME participation will be subject to the request of voting Committee members and will fall within the following guidelines:

- A. A SME may be invited to provide information on specific subjects and topics at the discretion of voting committee members, the Chair or Vice-Chair, and DSHS staff;
- B. An invited SME may be recognized by staff, the Committee Chair, or Vice-Chair to provide information or analysis during allotted time periods at a specified committee or subcommittee meeting;
- C. SMEs will participate in questions and answers at the direction of the staff, Committee Chair, or Vice-Chair;
- D. All SMEs will participate and serve at the pleasure of the Committee;
- E. SMEs do not hold any official capacity on the Committee or subcommittees and do not have rights of deliberation or the right to vote on any Committee activities or decisions;
- F. SMEs should disclose any conflicts of interest they may have prior to providing information to the Committee; and

- G. None of the information or guidance contained in this section shall prevent any person from participating in a Committee meeting or providing comments to the Committee as allowed under the Texas Open Meetings Act.

13. Responsibilities of Support Staff

The DSHS Newborn Screening Program will be present at and will provide reasonable administrative and technical support and coordination for all Committee and subcommittee activities. DSHS will coordinate as needed to provide the reasonable accommodations and supports needed by a Committee member requiring accommodations to enable him or her to fully participate in Committee and subcommittee meetings and activities.

Staff is expected to perform the following tasks:

- A. Develop effective working relationships with Committee members;
- B. Solicit nominations for membership in accordance with the appropriate DSHS and HHS procedures;
- C. Provide information and technical resources for reporting and submitting Committee recommendations to the DSHS Commissioner as needed.
- D. Serve as liaison between members and operating agencies' staff; and
- E. Plan, coordinate, and organize Committee and subcommittee meetings and activities, including:
 - 1. Schedule meeting dates and ensure meeting sites are set up;
 - 2. Notify members of upcoming meeting dates, times, and locations;
 - 3. Develop the agenda and support materials for each meeting in collaboration with the presiding officers;
 - 4. Prepare and oversee that the agenda is posted on the Secretary of State's Open Meetings website in a timely manner and on the HHS website;
 - 5. Serve as point of contact for the public, including ensuring that contact information, agendas, and meeting support materials are easily accessible on the HHS website;
 - 6. Prepare and distribute information and materials for member review; and
 - 7. Prepare and maintain Committee records and documentation in accordance with the DSHS records retention policy.
- F. Coordinate as needed to provide reasonable accommodations and supports required for a Committee member who has a disability to enable the member to fully participate in Committee meetings and activities; and
- G. Perform other duties within staff discretion provided the necessary resources are available.

14. Compensation and Travel Reimbursement

A member of the Newborn Screening Advisory Committee is not entitled to any compensation (stipend) or reimbursement of expenses. DSHS has identified that the Newborn Screening Advisory Committee is not included in the General Appropriations Act, beginning with the 2016-2017 biennium, as being eligible for travel reimbursement.

Bylaws amended on _____ by a two-thirds vote of members attending the meeting.

Chairperson
Printed Name

Signature

DSHS
Printed Name

Signature

Statement by Members

- The Texas Department of State Health Services (DSHS), Texas Health and Human Services Commission (HHSC) and the Newborn Screening Advisory Committee (Committee) are not bound in any way by any statement or action on the part of any Committee member except when a statement or action is in pursuit of specific instructions from DSHS, or the Committee.
- The Committee and its members may not claim or appear to represent HHSC, DSHS, or the Committee in any legislative or advocacy activity without approval from the Committee chair and the Health and Human Services (HHS) Ethics Office in coordination with the HHSC Government and Stakeholder Relations Office. Committee members are not prohibited from discussing a report that has been formally adopted by this Committee, so long as members do not purport to represent HHSC or DSHS. Committee members are not prohibited from representing themselves or other entities in the legislative or advocacy process.
- A Committee member may not accept payment for services that are requested because of the members' title or position on this Committee.
- A Committee member shall not accept or solicit any benefit that might reasonably tend to influence the member in the discharge of the member's official Committee duties.
- A Committee member shall not knowingly solicit, accept, or agree to accept any benefit for having exercised the member's official powers or duties in favor of another person.
- A Committee member shall complete the Texas Open Meetings Act Training and the Public Information Act Training within 90 days of appointment and submit the Certificates of Completion to the Committee Liaison. A member who has taken the training within the last five years may submit a copy of the Certificate of Completion to the Committee Liaison in lieu of retaking the training.
- Nondisclosure agreement. A Committee member may not disclose confidential information or agency-generated information in draft form, acquired through his or her Committee membership, unless HHSC or DSHS has released and made public the information or document, the DSHS Commissioner or HHS Executive Commissioner has approved the release in writing, or the HHS Ethics Office permits release. This requirement survives the member's tenure on the Committee. In addition, the member must confirm that he or she will require the member's interpreters, attendants, or other support persons, if any, to comply with this requirement. For purposes of the Nondisclosure Agreement, the term "confidential information" includes all information protected by the Health Insurance Portability and Accountability Act (HIPAA), information that has commercial value or use, such as trade secrets, and information communicated in confidence by the HHS System.
- Conflict of Interest Statement. A Committee member agrees to disclose any personal or private interest that the member or their family have in a measure, proposal, or decision pending before DSHS or HHSC. ("Personal or private interest" does not include the member's engagement in a profession, trade, or occupation when the member's interest is the same as all others similarly engaged in the profession, trade, or occupation, or if the member merely provides a personal experience, with no personal or private financial interest, in giving feedback on the subject matter.) If there is a direct personal or financial interest in a motion under consideration, the member further agrees to disclose

that fact in a public meeting and will recuse themselves from any Committee deliberations or decisions on that matter.

I have been provided a copy of the Newborn Screening Advisory Committee Bylaws. I understand that as a member of the Committee I must adhere to the Bylaws.

Advisory Committee Member Signature

Printed Name

Date

Revisions Tracking Page

Document Version #	Revision Date	Revisions / Purpose	Author
1	7/16/2018	Section 14 deleted and training requirement added by Committee vote.	Patricia Lanfranco
2	10/19/2018	Added Section 14 language back into document in compliance with agency policy.	Aimee Millangue
3	10/2/2020	Revised Section 7 language to clarify the length and number of terms served by the Chair and Vice-Chair and when office terms expire.	Aimee Millangue
4	3/24/2023	<p>Revised language to comply with agency guidance as follows:</p> <p>Listed Texas Administrative Code authorizing the Committee;</p> <p>Added definitions;</p> <p>Added that the total number of voting members is 13;</p> <p>Changed and added conditions regarding the maximum number of terms members may serve;</p> <p>Removed requirement that the Chair or Vice-Chair must preside over meetings;</p> <p>Changed the method by which members may attend and participate in meetings from "telephone conference" to "in-person and video conference call" in compliance with law;</p> <p>Added requirements for revising Bylaws;</p> <p>Removed requirement that the Chair may require members to travel to Austin for meetings;</p> <p>Clarified member expectations and removal from the Committee;</p> <p>Clarified and updated responsibilities of support staff;</p> <p>In the Statement by members, added references to the HHSC and spelled out acronyms on first mention; and</p> <p>Made non-substantive edits such as spelling, grammar, and formatting.</p>	Aimee Millangue