

Sickle Cell Advisory Committee

Bylaws

1. Name and Legal Authority

The Sickle Cell Advisory Committee (Committee) is established under Texas Government Code, § 531.012, and 25 TAC §37.420 that established the tasks, reporting requirements, membership requirements, membership qualifications, and meeting schedules.

Texas Government Code § 2110.008 (Duration of Advisory Committees) applies to the Sickle Cell Advisory Committee. This Committee is abolished on September 1, 2018.

2. Purpose and Role

The purpose of the Committee is to raise awareness of Sickle Cell Disease and Sickle Cell Trait in Texas, and advise the Texas Health and Human Services Commission on matters as described below:

A. Tasks

1. Review and suggest methods for raising public awareness.
2. Recommend two specific strategies in the two-year term to raise public awareness.

The Committee submits reports as described below:

- A. The Committee files an annual written report with the Health and Human Services Executive Commissioner.
- B. The report covers the meetings and activities in the immediate preceding fiscal year and is filed with the HHS Executive Commissioner by the first day of December of the following fiscal year.
- C. The Committee reports any recommendations to the HHS Executive Commissioner at a meeting of the HHS Executive Council established under Government Code § 531.0051.
- D. The Committee files an annual report with the Texas Legislature of any policy recommendations made to the HHS Executive Commissioner.

3. Definitions or Acronyms

DSHS - Texas Department of State Health Services
HHSC - Texas Health and Human Services Commission
HHS - Health and Human Services
NBS - Newborn Screening Program
SCD - Sickle Cell Disease
SCT - Sickle Cell Trait
TAC - Texas Administrative Code

4. Committee Composition

The Committee is composed of seven voting members appointed by the HHS Executive Commissioner as described in 25 TAC §37.420.

This membership includes:

- A. Two members from community based organizations with experience addressing the needs of individuals with SCD;
- B. Two physicians specializing in hematology;
- C. Two members of the public who are either an individual with SCD or a parent of a person with SCD or SCT; and
- D. One representative from a health professions academic setting.

To the greatest extent possible, DSHS and the HHS Executive Commissioner appoints members who reflect the diversity of the state.

5. Member Terms

The expiration of membership terms occurs on September 1, 2018. Regardless of the term limit, a member serves until his/her replacement has been appointed. This ensures 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 HHS Executive Commissioner and 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. Persons who submitted applications within the previous year through the DSHS may be reconsidered for membership.

7. Presiding Chair and Vice-Chair

In accordance with Government Code Chapter 2110, the Committee selects from its members a Chair and Vice-Chair. The Chair and Vice-Chair will serve a term of two years. In the event that the Chair is unable to complete his/her term for any reason, a new chair will be elected.

The Vice-Chair performs the duties of the Chair in case of the absence or disability of the Chair. In case the Chair position becomes vacant, the Vice-Chair serves until the Committee selects a new Chair. In the event that the Vice-Chair is unable to complete his/her term for any reason, a new Vice-Chair will be elected.

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 to accomplish the work of the Committee;
- F. Ensure the Committee adheres to its charge;
- G. Call for the development of subcommittees (if applicable and with approval of agency staff); and
- H. 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 three times a year to conduct business.

2. The Committee is subject to Texas Government Code Chapter 551 (the Texas Open Meetings Act) as if it were a governmental body.

B. Quorum

A majority of voting members constitutes a quorum for the purpose of transacting official business. To calculate a majority for a Committee an odd number of members, divide the membership by two and round up to the next whole number; thus, a quorum is four voting members. 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 that is 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 that could present, or reasonably appear to present, a conflict of interest.
2. The Committee may determine procedural matters by a majority vote of the members attending the meeting, or may use Robert's Rules of Order as a guide to its operations and proceedings.
3. Committee members may also vote on operational or procedural matters that come before the Committee.
4. A member may participate and vote by telephone conference as deemed necessary by agency staff.
5. A member may not authorize another individual to represent the member by proxy.
6. For all business except adopting or amending bylaws, a simple majority is needed. (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.)
7. Except for bylaw adoption and amendments, Committee recommendations will be adopted pursuant to a simple majority vote on a motion duly made and seconded.

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 for inclusion in the publication of the agenda in the *Texas Register* and distribution to the members for their consideration. Amendments 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.
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 by the Committee. The Committee will make note of the date of the adoption of the Bylaws in its minutes. Members will sign a Statement by Members when bylaws are amended (see attached Statement).

9. Responsibilities of Members

A. Attendance

Members are expected to attend all meetings. Meetings may be conducted in person, through teleconference call, or by means of other technology. 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, other than ex officio/state agency representative members, may not send a substitute to attend a meeting in their place.

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

B. Member expectations:

1. Attend meetings which may be conducted in person, through teleconference call, or by means of other technology;

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 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. If a member has taken the trainings within the last five years, a copy of the Certificates of Completion may be submitted to the Committee Liaison in lieu of taking 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 HHSC'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 in draft form, until such time as the information or document is released and made public, the 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. 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. Participate in legislative or advocacy activities using his/her title or position on this Committee without written approval from the Committee Chair and the HHS Ethics Office in coordination with the HHS Government Relations Office and the Committee Liaison; however, members may represent themselves or other entities in the legislative process.
2. Accept payment for any services offered to the member because of his/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 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 are grounds for dismissal and may result in removal from the Committee.

10. Removal from the Committee

The HHS Executive Commissioner may remove a member from the Committee 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 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 they were filling.
- E. A member participates in legislative or advocacy activities using his/her title or position on the Committee without approval from the Committee Chair and the HHS Ethics Office in coordination with the HHS Government Relations Office and Committee Liaison.
- F. A member receives payment for any services requested because he or she holds a position on the Committee.
- G. A member discloses confidential or draft information acquired through his or her participation on the Committee not in accordance with the Bylaws.
- H. A member, in a 12-month period, misses three meetings with or without notice to DSHS staff.
- I. The HHS Executive Commissioner may remove a member who has violated the conflict of interest provisions or made a statement in violation of the Statements by Members form.

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 charge 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 HHS Executive 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 the Texas Open Meetings Act; and
 - 2. Requires the subcommittee meeting to be held in compliance with 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 charge(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 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, 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;
- G. None of the information or guidance contained in this section shall prevent any individual from participating in 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 provide reasonable administrative and technical support and coordination for all Committee and subcommittee activities. DSHS will coordinate as needed to provide the accommodations and supports needed by a Committee member requiring accommodations to enable him/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 HHS procedures;
- C. Support the Committee by providing requested information, including data, in the write-up and submission of the annual report to the HHS Executive Commissioner;
- D. Serve as liaison between members and operating agencies' staff; and
- E. Plan, coordinate, and organize Committee and subcommittee meetings and activities, including but not limited to:
 - 1. Schedule meeting dates and ensure meeting sites are set up;
 - 2. Notify members of upcoming meeting dates, times, and locations;
 - 3. Develop agenda and support materials for each meeting;
 - 4. Prepare and oversee that the agenda is posted in the *Texas Register* in a timely manner and on the DSHS NBS website;
 - 5. Serve as point of contact for the public including ensuring contact information, agendas, and meeting support materials are easily accessible on the DSHS NBS 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. Staff may perform other duties within staff discretion provided the necessary resources are available.

14. Compensation and Travel Reimbursement

A member of the Sickie Cell Advisory Committee is not entitled to any compensation (stipend) or reimbursement of expenses.

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

Chairperson
Printed Name

Signature

DSHS
Printed Name

Signature

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Statement by Members

- The DSHS, HHSC, and the Sickle Cell 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 HHSC or the Committee.
- The Committee and its members may not participate in legislative or advocacy activities using his/her title or position on this Committee without approval from the Committee chair and the HHS Ethics Office in coordination with the Government Relations Office. 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. If a member has taken the training within the last five years, a copy of the Certificate of Completion may be submitted to the Committee Liaison in lieu of taking 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 has released and made public the information or document, the 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. 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. I agree to disclose any personal or private interest that myself or my 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, I further agree to disclose that fact in a public meeting and will recuse myself from any Committee deliberations or decisions on that matter.

I have been provided a copy of the Sickle Cell Advisory Committee bylaws. I understand that as a member of the Committee I must adhere to the bylaws.

Advisory Board Member Signature

Printed Name

Date

Revisions Tracking Page

Document Version #	Revision Date	Revisions / Purpose	Author
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