

Sunset Public Hearing Questions for  
**Hemophilia Advisory Committee**  
Created by Section 68-41-103, *Tennessee Code Annotated*  
(Sunset termination June 2015)

- 1. Provide a brief introduction to the Hemophilia Advisory Committee, including information about its purpose, statutory duties, staff, and administrative attachment. Also describe the Hemophilia Program, its major activities, and its staffing.**

**The Hemophilia Advisory Committee** was established in 1973 to advise the Department in developing standards for determining eligibility, to assist in development and expansion of care and extend financial assistance in order to provide diagnosis and treatment of persons with hemophilia and other genetic bleeding disorders.

The Committee consists of seven members appointed by the Commissioner of Health for four-year terms, serving until successors are appointed. There is one representative each from hospitals, medical schools, blood banks, voluntary agencies interested in hemophilia, local public health agencies, medical specialists in hemophilia, and the general public. The committee meets as frequently as the commissioner deems necessary, but not less than once each year. The Department provides administrative support.

**The Hemophilia Program**, 100% State funded, provides financial assistance to persons suffering from hemophilia and other genetic bleeding disorders who require continuing treatment with blood and blood derivatives to avoid crippling, extensive hospitalization and other effects associated with this bleeding condition, but who are unable to pay for the entire cost of such services on a continuing basis despite the existence of various types of hospital and medical insurance. Participants must be financially eligible (300% of the Federal Poverty Guideline) and meet the medical criteria. The Department of Health contracts with five (5) comprehensive care centers to coordinate ongoing expert care - UT Memphis, VUMC, UT Knoxville, ETSU, and T.C. Thompson Children's Hospital. There are 198 current Program participants. An annual financial update is required for proof of continued eligibility.

The Hemophilia Program is staffed by a Registered Nurse who serves as the Program Director and an Administrative Services Assistant 2.

- 2. Provide a list of current members of the committee. For each member please indicate who appointed the member, how the member's presence on the committee complies with Section 68-41-103, *Tennessee Code Annotated*, and the member's county of principal residence. Please indicate each member's race and gender and which members, if any, are 60 years of age or older. Are there any vacancies on the committee? If so, what is being done to fill those vacancies?**

<u>Member</u>	<u>Race/Gender</u>	<u>Representative</u>
Dr. Marion Dugdale Shelby County	C/F over 60	Hospitals
Dr. Wahid Hanna Knox County	C/M	Medical Specialist
Nikita A. Lyons-Murry Rutherford County	AA/F	Voluntary Agencies
Jocelynn McCall Davidson County	C/F	Blood Banks, American Red Cross
Dr. Lawrence S. Moffatt Washington County	C/M over 60	Local Public Health
Dr. Jan Van Eys Davidson County	C/M over 60	Medical Schools
Carolyn Wright Williamson County	C/F	General Public

**3. How many times did the committee meet in fiscal years 2008 - 2013, and how many members were present at each meeting?**

The Committee has met three times since 2008. Five members were present in 2008 and 2010. Two members were present in 2009 which did not represent a quorum. Despite aggressive outreach on the part of the Program Director, a quorum could not be established to meet in 2011, 2012 and 2013.

**4. What per diem or travel reimbursement do members of the committee receive? How much was paid to committee members during fiscal years 2008 - 2013?**

Members are reimbursed for travel expenses, as stated in TCA 68-41-103, in accordance with the State Comprehensive Travel Regulations. No expenses were paid during this time.

**5. What were the committee's revenues (by source) and expenditures (by object) for fiscal year 2018 -2013? Does the committee carry a fund balance and, if so, what is the total of that fund balance? If expenditures exceeded revenues, and the committee does not carry a fund balance, what was the source of the revenue for the excess expenditures?**

The Committee has no revenue or expenditures.

- 6. Is the committee subject to Sunshine law requirements (Section 8-44-101 et seq., *Tennessee Code Annotated*) for public notice of meetings, prompt and full recording of minutes, and public access to minutes? What procedures does the committee have for informing the public of its meetings and making its minutes available to the public?**

The Committee is subject to Sunshine law requirements. A notice of a meeting, which includes the agenda, is provided to the Department's Public Information Office for publication the month preceding the meeting. The minutes are kept on file in the Department of Health and available to anyone upon request.

- 7. Describe the nature and extent of the committee's activities and any major accomplishments of the past two years. Specifically, detail the committee's actions to advise the Department of Health in the areas set forth in Section 68-41-104.**

There has been no activity other than the three meetings detailed in # 3 above. In the absence of a quorum no official business could be conducted.

- 8. How does the committee ensure that its members and staff are operating in an impartial manner and that there are no conflicts of interest? If the committee operates under a formal conflict of interest policy, please attach a copy of that policy.**

Committee members are requested to sign a conflict of interest statement.

- 9. Has the committee set goals and measured its performance compared to the goals? What performance indicators or goals does management use to measure the effectiveness and efficiency of the committee? How well has the committee performed based on those performance indicators?**

No goals were set.

- 10. Describe any items related to the committee that need legislative attention and your proposed legislative changes.**

There have been no items identified which need legislative attention. There are no proposed legislative changes.

- 11. Should the committee be continued? To what extent and in what ways would the absence of the committee affect the public health, safety, or welfare?**

The Department recommends that TCA 68-41-103 be allowed to sunset as scheduled. The absence of the Committee would not affect the public health, safety, or welfare of the citizens of Tennessee. When the Committee was established in 1973, the Department relied on the Advisory Committee for recommendations of policies, eligibility and treatment of persons with Hemophilia and other genetic bleeding

disorders. Clinical expertise is now readily available through the five Hemophilia Comprehensive Care Clinics. Standards of Care are well established and policies for eligibility are adjusted with the Federal Poverty Guideline.

The Department consistently provides necessary recommendations to the Commissioner and Governor.

**Questions 12 – 18 do not apply to the Hemophilia Advisory Committee**

12. Please list all committee programs or activities that receive federal financial assistance and, therefore are required to comply with Title VI of the Civil Rights Act of 1964. Include the amount of federal funding received by program/activity.

[Federal financial assistance includes:

- (1) Grants and loans of Federal funds,
- (2) The grant or donation of Federal Property and interests in property,
- (3) The detail of Federal personnel,
- (4) The sale and lease of, and the permission to use (on other than a casual or transient basis), Federal property or any interest in such property without consideration or at a nominal consideration, or at a consideration which is reduced for the purpose of assisting the recipient, or in recognition of the public interest to be served by such sale or lease to the recipient, and
- (5) Any federal agreement, arrangement, or other contract which has as one of its purposes the provision of assistance.

28 C.F.R. Sec. 42.102(c)]

[The term recipient means any State, political subdivision of any State, or instrumentality of any State or political subdivision, any public or private agency, institution, or organization, or other entity, or any individual, in any State, to whom Federal financial assistance is extended, directly or through another recipient, for any program, including any successor, assign, or transferee thereof, but such term does not include any ultimate beneficiary under any such program.

28 C.F.R. Sec. 42.102(f)]

***If the committee does receive federal assistance, please answer questions 14 through 21. If the committee does not receive federal assistance, proceed directly to question 20.***

13. Does your committee prepare a Title VI plan? If yes, please provide a copy of the most recent plan.

14. Does your committee have a Title VI coordinator? If yes, please provide the Title VI coordinator's name and phone number and a brief description of his/her duties. If not,

provide the name and phone number of the person responsible for dealing with Title VI issues.

15. To which state or federal agency (if any) does your committee report concerning Title VI? Please describe the information your committee submits to the state or federal government and/or provide a copy of the most recent report submitted.
16. Describe your committee's actions to ensure that committee staff and clients/program participants understand the requirements of Title VI.
17. Describe your committee's actions to ensure it is meeting Title VI requirements. Specifically, describe any committee monitoring or tracking activities related to Title VI, and how frequently these activities occur.
18. Please describe the committee's procedures for handling Title VI complaints. Has your committee received any Title VI-related complaints during the past two years? If yes, please describe each complaint, how each complaint was investigated, and how each complaint was resolved (or, if not yet resolved, the complaint's current status).
- 19. Please provide a breakdown of current committee staff by title, ethnicity, and gender.**

The committee has no staff solely dedicated to its activities. Donna Hurst, Nursing Consultant and Assistant to CHS Medical Director, is Caucasian, Female.

- 20. Please list all committee contracts, detailing each contractor, the services provided, the amount of the contract, and the ethnicity of the contractor/business owner.**

The committee has no contracts.

## Supplemental Questions Regarding the Hemophilia Advisory Committee

TCA 68-41-103 established the Hemophilia Advisory Committee in 1973 to advise the Department of Health in developing standards for determining eligibility, to assist in development and expansion of care and to extend financial assistance in order to provide diagnosis and treatment of persons with hemophilia and other genetic bleeding disorders.

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The absence of the Committee would not affect the public health, safety, or welfare of the citizens of Tennessee. When the Committee was established in 1973, the Department relied on the Advisory Committee for recommendations of policies, eligibility and treatment of persons with Hemophilia and other genetic bleeding disorders. Clinical expertise is now readily available through the five Hemophilia Comprehensive Care Clinics. Standards of Care are well established and policies for eligibility are adjusted with the Federal Poverty Guideline.

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1. What are your key measures for ensuring that your organization is meeting its goals?  
NA
2. What are the statistical reliability and accuracy (for objective measures) or validity and repeatability (for subjective measures) of your key measures?  
NA
3. What is the record (over time) of those key measures in relation to what they should be to accomplish the goal of the organization? (I would like to see charts that have a performance mean and 3-standard deviation limits marked on them for these measures. Note: if these cannot be provided, I would like a valid explanation and a plan for future implementation.)  
NA
4. Explain any excessive variation in your key measures.  
NA

5. What unique events or special causes have driven your key measures beyond 3 standard deviations from the mean in the past and what have done about them?

NA

6. What impediments, if any, prevent you from driving those key measures to the desired point?

NA

7. How are you addressing/correcting the impediments, if any, that prevent you from driving those key measures to the desired point?

NA