

2024 Current Fiscal Year Report: Sickle Cell Disease Advisory Committee

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1. Department or Agency

Department of Health and Human
Services

2. Fiscal Year

2024

3. Committee or Subcommittee

Sickle Cell Disease Advisory
Committee

3b. GSA Committee

No.

1026

4. Is this New During Fiscal Year?

No

5. Current Charter

06/30/2023

6. Expected Renewal Date

06/30/2025

7. Expected Term Date

8a. Was Terminated During Fiscal Year?

No

8b. Specific Termination Authority

8c. Actual Term Date

9. Agency

Recommendation for Next Fiscal Year

Continue

10a. Legislation Req to Terminate?

Not Applicable

10b.

Legislation Pending?

Not Applicable

11. Establishment Authority

Authorized by Law

12. Specific Establishment Authority

42 U.S.C. 282(b)(16)

13. Effective Date

11/04/1988

14. Committee Type

Continuing

14c. Presidential?

No

15. Description of Committee

Scientific Technical Program
Advisory Board

16a. Total

Number of Reports

No Reports for
this Fiscal Year

17a.

Open

0

17b. Closed

0

17c. Partially Closed

0

Other Activities

0

17d. Total

0

Meetings and Dates

No Meetings

Current Next

FY

FY

18a(1). Personnel Pmts to Non-Federal Members	\$0.00 \$0.00
18a(2). Personnel Pmts to Federal Members	\$0.00 \$0.00
18a(3). Personnel Pmts to Federal Staff	\$0.00 \$0.00
18a(4). Personnel Pmts to Non-Member Consultants	\$0.00 \$0.00
18b(1). Travel and Per Diem to Non-Federal Members	\$0.00 \$0.00
18b(2). Travel and Per Diem to Federal Members	\$0.00 \$0.00
18b(3). Travel and Per Diem to Federal Staff	\$0.00 \$0.00
18b(4). Travel and Per Diem to Non-member Consultants	\$0.00 \$0.00
18c. Other(rents,user charges, graphics, printing, mail, etc.)	\$0.00 \$0.00
18d. Total	\$0.00 \$0.00
19. Federal Staff Support Years (FTE)	0.00 0.00

20a. How does the Committee accomplish its purpose?

The Sickle Cell Disease Advisory Committee is composed of highly qualified individuals with expertise in the areas of basic and clinical research, translational science, genetics and community programs related to sickle cell disease, as well as members of the patient community with leadership in programs related to sickle cell disease and government agencies that have oversight responsibility for health care delivery to individuals with genetic disorders. The Committee makes recommendations on research priorities conducted or supported by the Institute. The Committee also makes recommendations and develops long range plans of basic, clinical, applied, health education, and prevention related

research concerning the scientific aspects of research programs on the nature, causes, diagnosis, treatment, and prevention of Sickle Cell Disease. NHLBI in turn provides feedback and updates its response to action items generated at each meeting.

20b. How does the Committee balance its membership?

The Committee consists of 15 appointed members, five selected from authorities knowledgeable in clinical fields related to sickle cell disease, three members selected from experts in basic science fields related to sickle cell disease, three members selected from experts in translational science, and four public members selected with demonstrated leadership in programs related to sickle cell disease. The strength of the Committee is the diversity of its membership that represents disciplines from basic science to public health administration. It is further augmented by three ex officio members, one each from the following agencies: the National Institute of Health, the Center for Disease Control and Prevention, and the Health Resources and Services Administration.

20c. How frequent and relevant are the Committee Meetings?

The Committee meets approximately two times within a fiscal year. These meeting(s) include scientific presentations of ongoing or pending projects by the scientific and medical community, program review of current and planned efforts by the NHLBI, as well as open discussion regarding programmatic needs and direction. Members are asked to contribute expertise and specific efforts for future initiatives, conferences, and further advisory efforts that might prove helpful. The

Sickle Cell Disease Advisory Committee held one meeting in FY23, on January 30, 2023. During the January 30, 2023 meeting, the Committee received updates from NHLBI staff on major NHLBI funded programs in sickle cell disease. The committee then heard presentations by three invited speakers, Dr. Lanzkron, Dr. Fasipe, and Ms. Heather Avant. Dr. Lanzkron presented research on engaging the sickle cell community in clinical research. Dr. Fasipe provided the history of sickle cell disease and scientific discoveries and provided her perspective on the challenges of living with sickle cell disease. Ms. Avant shared her perspective on research and clinical trials and living with sickle cell disease. There were no recommendations submitted by the Committee to the Institute in FY23.

20d. Why can't the advice or information this committee provides be obtained elsewhere?

This Committee, with professional and public members, is knowledgeable about sickle cell disease and biology relevant to sickle cell pathogenesis, including the most recent advanced treatments. The Committee serves as an effective mechanism for "bridging the gap" between the Federal programs and the community, and for providing advice to the National Sickle Cell Program. It provides an important focus for obtaining information from all Federal agencies that is not available through other mechanisms.

20e. Why is it necessary to close and/or partially closed committee meetings?

N/A

21. Remarks

Reports: This committee did not produce any public reports. The DFO and Committee Decision

Maker positions are held by the same individual based on assigned duties within the Institute.

Members: Four members' terms ended in FY2023 (Hankins, Lanzkron, Smith and Wood). Four new members joined the committee in FY2023 (Chao, Woolford, Green, and Fasipe). There were no recommendations made by the Committee in FY 2023. Dr. Lawrence Tabak's title was updated from Performing the Duties of the NIH Director to Acting Director, NIH this fiscal year.

Designated Federal Officer

Julie Panepinto Director, Division of Blood Diseases and Resources

Committee Members	Start	End	Occupation	Member Designation
				Special
Bauer, Daniel	09/12/2021	06/30/2024	Assistant Professor of Pediatrics, Harvard Medical School	Government Employee (SGE) Member
Brown-Watts, Velvet	02/14/2022	06/30/2024	Founder & Chairperson, Supporters of Families with Sickle Cell Disease	Special Government Employee (SGE) Member
Chou, Stella	04/23/2023	06/30/2026	Associate Professor, Perelman School of Medicine, University of Pennsylvania	Special Government Employee (SGE) Member
Fasipe, Titilope	07/30/2023	06/30/2026	Assistant Professor, Baylor College of Medicine	Special Government Employee (SGE) Member
Gladwin, Mark	02/14/2022	06/30/2024	Dean, School of Medicine, University of Maryland	Special Government Employee (SGE) Member
Green, Nancy	07/01/2023	06/30/2027	Associate Dean for Academic Operations and Advancement, College of Physicians and Surgeons, Columbia University	Special Government Employee (SGE) Member

Hsu, Lewis	06/06/2021	06/30/2024	Professor of Clinical Pediatrics, Department Special of Pediatric Government Hematology-Oncology, Employee University of Illinois at (SGE) Chicago College of Member Medicine
Key, Nigel	06/06/2021	06/30/2024	Professor and Director, Department of Medicine, Blood Research Center, Special Government Employee (SGE) University of North Member Carolina at Chapel Hill
Krishnamurti, Lakshmanan	03/27/2022	06/30/2025	Professor and Section Chief, Yale University Special Government Employee (SGE) Member
Tabak, Lawrence	12/20/2021	01/20/2025	Acting Director, NIH Ex Officio Member
Treadwell, Marsha	09/26/2021	06/30/2024	Professor and Clinical Scientist, Children's Hospital and Research Center at Oakland, Special Government Employee (SGE) University of California Member San Francisco
Trimnell, Cassandra	03/27/2022	06/30/2024	Founder and Executive Director, Sick Cell 101 Special Government Employee (SGE) Member
Woolford, Teonna	05/07/2023	06/30/2026	Founder and CEO, Sick Cell Reproductive Health Education Directive Special Government Employee (SGE) Member

Number of Committee Members Listed: 13

Narrative Description

NIH's mission is to seek fundamental knowledge about the nature and behavior of living systems and the application of that knowledge to enhance health, lengthen life, and reduce illness and disability. NIH works toward that mission by the establishment of a Sick Cell Disease Advisory Committee to provide advice and guidance concerning the Sick Cell Disease Program, Division of Blood Diseases and Resources, National Heart, Lung, and Blood Institute.

What are the most significant program outcomes associated with this committee?

Checked if
Applies

Improvements to health or safety	<input checked="" type="checkbox"/>
Trust in government	<input type="checkbox"/>
Major policy changes	<input type="checkbox"/>
Advance in scientific research	<input type="checkbox"/>
Effective grant making	<input type="checkbox"/>
Improved service delivery	<input type="checkbox"/>
Increased customer satisfaction	<input type="checkbox"/>
Implementation of laws or regulatory requirements	<input type="checkbox"/>
Other	<input type="checkbox"/>

Outcome Comments

N/A

What are the cost savings associated with this committee?

Checked if Applies

None	<input checked="" type="checkbox"/>
Unable to Determine	<input type="checkbox"/>
Under \$100,000	<input type="checkbox"/>
\$100,000 - \$500,000	<input type="checkbox"/>
\$500,001 - \$1,000,000	<input type="checkbox"/>
\$1,000,001 - \$5,000,000	<input type="checkbox"/>
\$5,000,001 - \$10,000,000	<input type="checkbox"/>
Over \$10,000,000	<input type="checkbox"/>
Cost Savings Other	<input type="checkbox"/>

Cost Savings Comments

NIH supported basic and clinical research accomplishments often take many years to unfold into new diagnostic tests and new ways to treat and prevent diseases.

What is the approximate Number of recommendations produced by this committee for the life of the committee?

Number of Recommendations Comments

There were no specific recommendations made by the Committee in FY 2023. During the January 30, 2023 meeting, the Committee received updates from NHLBI staff on major NHLBI funded programs in sickle cell disease. The committee then heard presentations by three invited speakers, Dr. Lanzkron, Dr. Fasipe, and Ms. Heather Avant. Dr. Lanzkron presented research on engaging the sickle cell community in clinical research. Dr. Fasipe provided the history of sickle cell disease and scientific discoveries and provided her perspective on the challenges of living with sickle cell disease. Ms. Avant shared her perspective on research and clinical trials and living with sickle cell disease.

What is the approximate Percentage of these recommendations that have been or will be Fully implemented by the agency?

0%

% of Recommendations Fully Implemented Comments

Due to the complexity of the recommendations made by this committee, staff is unable to determine which recommendations have been fully or partially implemented solely in response to this committee's activities.

What is the approximate Percentage of these recommendations that have been or will be Partially implemented by the agency?

0%

% of Recommendations Partially Implemented Comments

Due to the complexity of the recommendations made by this committee, staff is unable to determine which recommendations have been fully or partially implemented solely in response to this committee's activities.

Does the agency provide the committee with feedback regarding actions taken to implement recommendations or advice offered?

Yes ☒ No ☐ Not Applicable ☐

Agency Feedback Comments

Information is provided to the public at each meeting. The public can view information related to the Committee through the committee's official website.

What other actions has the agency taken as a result of the committee's advice or recommendation?

Checked if Applies

Reorganized Priorities	<input type="checkbox"/>
Reallocated resources	<input type="checkbox"/>
Issued new regulation	<input type="checkbox"/>
Proposed legislation	<input type="checkbox"/>
Approved grants or other payments	<input type="checkbox"/>
Other	<input type="checkbox"/>

Action Comments

N/A

Is the Committee engaged in the review of applications for grants?

No

Grant Review Comments

N/A

How is access provided to the information for the Committee's documentation?

Checked if Applies

Contact DFO	<input checked="" type="checkbox"/>
Online Agency Web Site	<input checked="" type="checkbox"/>
Online Committee Web Site	<input checked="" type="checkbox"/>
Online GSA FACA Web Site	<input checked="" type="checkbox"/>
Publications	<input type="checkbox"/>
Other	<input type="checkbox"/>

Access Comments

N/A