2026 Current Fiscal Year Report: Sickle Cell Disease Advisory Committee

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1. Department or Agency	2. Fiscal Year
Department of Health and Human Services	2026

3. Committee or Subcommittee	3b. GSA Committee No.
Sickle Cell Disease Advisory Committee	1026

4. Is this New During Fiscal Year?	5. Current Charter	6. Expected Renewal Date	7. Expected Term Date
No	09/24/2025	09/24/2027	

8a. Was Terminated During FiscalYear?	8b. Specific Termination Authority	8c. Actual Term Date
Yes		06/30/2025

9. Agency Recommendation for Next FiscalYear	10a. Legislation Req to Terminate?	10b. Legislation Pending?
Continue	Not Applicable	Not Applicable

11. Establishment Authority Authorized by Law

12. Specific Establishment Authority	13. Effective Date	14. Commitee Type	14c. Presidential?
42 U.S.C. 282(b)(16)	11/04/1988	Continuing	No

15. Description of Committee Scientific Technical Program Advisory Board

16a. Total Number of Reports	No Reports for this FiscalYear

17a. Open	17b. Closed	17c. Partially Closed	Other Activities	17d. Total
1	0	0	0	1

Meetings and Dates

Purpose	Start	End
Program Advisory	05/26/2026	- 05/26/2026

Number of Committee Meetings Listed: 1

	Current FY	Next FY
18a(1). Personnel Pmts to Non-Federal Members	$1,400.00	$1,400.00
18a(2). Personnel Pmts to Federal Members	$0.00	$0.00
18a(3). Personnel Pmts to Federal Staff	$47,492.00	$47,492.00
18a(4). Personnel Pmts to Non-Member Consultants	$1,200.00	$1,200.00
18b(1). Travel and Per Diem to Non-Federal Members	$0.00	$6,855.00
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	$1,294.00
18c. Administrative Costs (FRNs, contractor support, In-person/hybrid/virtual meetings)	$2,171.00	$2,193.00
18d. Other (all other funds not captured by any other cost category)	$0.00	$0.00
18e. Total Costs	$52,263.00	$60,434.00
19. Federal Staff Support Years (FTE)	0.20	0.20

20a. How does the Committee accomplish its purpose?

The Sickle Cell Disease Advisory Committee (SCDAC) 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 (SCD), as well as members of the patient community with leadership in programs related to SCD and government agencies that have oversight responsibility for health care delivery to individuals with genetic disorders resulting in SCD. The SCDAC makes recommendations on research priorities conducted or supported by the National Heart, Lung, and Blood Institute(NHLBI). The Committee also makes recommendations and develops long-term plans for research related to SCD. This includes basic, clinical, applied, health education, and prevention-focused research with an emphasis on the scientific aspects of the disease's nature, causes, diagnosis, treatment, and prevention. NHLBI, in turn, provides feedback and updates its responses to the action items generated during 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. The Committee this year had 9 members, and one Ex Officio (Director of NIH).

20c. How frequent and relevant are the

Committee Meetings?
The Committee convenes one to two times per fiscal year. These meeting(s) include scientific presentations on ongoing or proposed projects from the scientific and medical communities, program review of current and planned NHLBI efforts, and open discussions on program needs and strategic direction. Committee members are expected to contribute their expertise and provide input on future initiatives, conferences, and further advisory efforts that may support the planning and advancement of NHLBI's SCD programs. There were 11 recommendations submitted by the Committee to the Institute in FY26.

20d. Why can't the advice or information this committee provides be obtained elsewhere?
This Committee, composed of both professional and public members, possesses expertise in SCD and the underlying biology of its pathogenesis, including knowledge of the latest advanced treatment approaches. The Committee serves as an effective mechanism for "bridging the gap" between the Federal programs and the stakeholder community comprised of individuals living with sickle cell disease, scientists, and healthcare providers. It provides an important focus for obtaining information that is not available through other mechanisms.

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

21. Remarks
Charter: The charter re-established on February 9, 2026 in FY26. Reports: This committee did not produce any reports this fiscal year. Member Number: The Committee this fiscal year had 9

members, and one Ex Officio (Director of NIH). Charter does not specify type or number of Ex Officios. Per the Charter, "officers or employees of the Department of Health and Human Services may be selected to serve as non-voting ex officio members as deemed necessary for the Committee to effectively carry out its functions." IC plans to fill gaps in expertise as nominations are approved and members are onboarded. This is why the Charter states 15 members but this ACR lists 7 current members. Members: Dr. Jonassaint's term ended early and has an updated end date of May 1, 2026. Two members, Drs. Chou and Fasipe, were administratively extended and have updated end date of 12/27/2026. The DFO and Committee Decision Maker positions are held by the same individual based on assigned duties within the Institute.

Designated Federal Officer

Julie Panepinto Director, Division of Blood Diseases and Resources

Committee Members	Start	End	Occupation	Member Designation
Bhattacharya, Jayanta	04/01/2025	01/20/2029	NIH Director	Ex Officio Member
Chou, Stella	04/23/2023	12/27/2026	Associate Professor, Perelman School of Medicine, University of Pennsylvania	Special Government Employee (SGE) Member
Fasipe, Titilope	07/30/2023	12/27/2026	Assistant Professor, Baylor College of Medicine	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

Jonassaint, Charles	03/24/2024	05/01/2026	Associate Professor, University of Pittsburgh	Special Government Employee (SGE) Member
Lance, Eboni	12/29/2024	06/30/2028	Medical Director	Special Government Employee (SGE) Member
Saraf, Santosh	12/29/2024	06/30/2028	Associate Director	Special Government Employee (SGE) Member
Sauntharajah, Yogen	01/28/2024	06/30/2027	Professor of Medicine, Lerner College of Medicine	Special Government Employee (SGE) Member
Sheehan, Vivien	03/24/2024	06/30/2027	Associate Professor of Pediatrics, Emory University School of Medicine	Special Government Employee (SGE) Member
Woolford, Teonna	05/07/2023	06/30/2026	Founder and CEO, Sickle Cell Reproductive Health Education Directive	Special Government Employee (SGE) Member

Number of Committee Members Listed: 10

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 supporting the research of non-Federal scientists in universities, medical schools, hospitals, and research institutions throughout the country and abroad. NIH works toward that mission by the establishment of a Sickle Cell Disease Advisory Committee to provide advice and guidance concerning the Sickle 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	✓
Trust in government	
Major policy changes	
Advance in scientific research	
Effective grant making	
Improved service delivery	
Increased customer satisfaction	
Implementation of laws or regulatory requirements	
Other	

Outcome Comments

N/A

What are the cost savings associated with this committee?

	Checked if Applies
None	✓
Unable to Determine	
Under $100,000	
$100,000 - $500,000	
$500,001 - $1,000,000	
$1,000,001 - $5,000,000	
$5,000,001 - $10,000,000	
Over $10,000,000	
Cost Savings Other	

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?

69

Number of Recommendations Comments

The first meeting of 2026 was held on May 26th to focus on Nutrition and Sickle Cell Disease (SCD) and the committee made 11 recommendations. Dr. Julie Panepinto emphasized the importance of this committee’s input in guiding NHLBI’s strategic direction, particularly in understanding the impact of a nutritional deficit in the overall health and wellness of individuals with SCD. The session's central theme — the intersection of nutrition and SCD — was described as both critically important and historically underexplored, with strong relevance to NIH's MAHA strategic framework. The Committee Chair, Dr. Fasipe, emphasized the value of whole-person care, lived-experience perspectives, and emerging areas such as gut microbiome research, nutritional health, and equitable food access. Presentation Summaries Dr. Lauren Klein — Nutrition and Growth in Children with SCD. Dr. Klein outlined the heightened nutritional vulnerability of children living with SCD, driven by the increased caloric and protein demands of chronic hemolysis, ongoing red blood cell production, inflammation, and elevated heart energy expenditure — factors often worsened by inadequate dietary intake and leading to growth delays. Citing research from Nigeria and high-income countries alike, she spotlighted food insecurity, shifting nutritional profiles, and the potential effects of hydroxyurea on growth as priority areas warranting further study across diverse settings. Dr. Ellen Fung — Micronutrients and Health Outcomes in SCD. Dr. Fung examined the landscape of micronutrient deficiencies in SCD, attributing them to a combination of poor diet, medication side effects, malabsorption, kidney-related nutrient loss, and an elevated metabolic rate. Deficiencies in vitamin D, folate, calcium, zinc, vitamin C, and protein are frequently observed. Among these, vitamin D and zinc carry the strongest evidence base: low vitamin D levels correlate with increased pain, inflammation, and emergency care use, while zinc deficiency is tied to stunted growth and greater complications. Notably, high-dose vitamin C and E supplementation showed no benefit and may be harmful. Significant gaps remain, including the lack of standardized nutritional assessments, SCD-specific dietary guidelines, and robust clinical trials across different genotypes and age groups. Dr. Amanda Brandow — The Gut Microbiome in SCD. Dr. Brandow shared research indicating that people with SCD have substantially reduced gut microbial diversity and a depletion of bacteria that produce short-chain fatty acids (SCFAs), compared to healthy controls. Lower microbial diversity was linked to more frequent acute pain episodes. Contributing factors to this gut imbalance include antibiotic exposure, opioid use, hydroxyurea, and disease-driven breakdown of the gut lining. Potential interventions under consideration include SCFA supplementation, prebiotics, probiotics, and targeted dietary changes. Comments on Recommendations The committee raised several cross-cutting concerns. Members acknowledged the dual challenge of undernutrition and obesity within the SCD population, questioned the adequacy of BMI as a sole assessment tool, and recommended DEXA scans for more

accurate body composition measurement. They advised against developing SCD-specific growth charts that might inadvertently frame poor growth as normal, and instead called for longitudinal data to better define healthy growth trajectories for this population. Food insecurity was identified as a major determinant of health outcomes. Other priorities raised included representation of all SCD genotypes in research, consideration of G6PD deficiency and organ dysfunction, and attention to caregiver and maternal mental health. Looking ahead, the committee underscored the importance of longitudinal patient registries, "food as medicine" policy frameworks, and cross-disciplinary collaboration as essential drivers of progress.

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	☐
Reallocated resources	☐
Issued new regulation	☐
Proposed legislation	☐
Approved grants or other payments	☐
Other	☐

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	✓
Online Agency Web Site	✓
Online Committee Web Site	✓
Online GSA FACA Web Site	✓
Publications	☐
Other	☐

Access Comments

N/A