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American Society of Hematology Statement to the
House Appropriations Subcommittee on Labor, HHS, Education, and Related Agencies
FY 2026 Funding for Public Health Agencies and Programs, Including NIH and CDC
April 9, 2025

The American Society of Hematology (ASH) appreciates the opportunity to provide outside witness testimony to the House Committee on Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies (Labor-HHS) for the FY 2026 Labor-HHS appropriations bill. We respectfully request that you consider the following requests:

- Support $51.303 billion for the National Institutes of Health (NIH).
- Support at least $11.581 billion for the Centers for Disease Control and Prevention (CDC), including $10 million for the Sickle Cell Disease Data Collection Program.
- Include ASH's report language on "Sickle Cell Trait" in the report that accompanies the FY 2026 Labor-HHS appropriations bill.

ASH represents more than 18,000 clinicians and scientists committed to the study and treatment of blood and blood-related diseases, including malignant disorders such as leukemia, lymphoma, and myeloma, as well as non-malignant conditions such as sickle cell disease (SCD), thalassemia, bone marrow failure, venous thromboembolism, and hemophilia. Hematologists have been pioneers in advancing understanding and treatment of various diseases and continue to be innovators in the fields of stem cell biology, regenerative medicine, transfusion medicine, and gene therapy. ASH membership is comprised of basic, translational, and clinical scientists, as well as physicians providing care to patients. Our mission is to foster high-quality care, transformative research, and innovative education to improve the lives of patients with blood and bone marrow disorders.

ASH is gravely concerned that the sweeping changes announced at the Department of Health and Human Services (HHS) may have profound unintended consequences and halt research progress and jeopardize care for patients with blood diseases. HHS and its agencies support critical research and care, and unilateral cuts or changes to those programs will be devastating to thousands of patients and their families. Research at the NIH supported the groundbreaking Food and Drug Administration (FDA) approval of the first gene therapy for SCD and more effective treatments for blood cancers, including chimeric antigen receptor (CAR) T-cell therapy, which has helped save countless lives when all other treatment options have failed. Projects like the CDC's Sickle Cell Data Collection program provide key insights into the care of individuals living with SCD, and Hemophilia Treatment Centers organized by the Health Resources & Services Administration (HRSA) provide essential care to individuals with hemophilia and other bleeding disorders.

Therefore, ASH urges the Labor-HHS subcommittee to ensure congressionally appropriated funds that support biomedical research and patient care for blood diseases are used as intended. We must not lose the momentum of decades of progress in hematology. Congress must preserve the United States' role as the world leader in cutting-edge research and patient care.

National Institutes of Health

Medical research funded through the NIH, the largest source of public funding for medical research in the world, has been a driving force behind many decades of advances that have improved the health of people in every state and community, providing cures and hope for patients and caregivers. NIH-supported hematologic research has also helped pave the way for many discoveries both within and outside of hematology. Discoveries made by hematologists have led to extraordinary advances in other fields of medicine, including new and better treatments for some of the world's deadliest and costliest diseases such as heart disease and stroke. Critical hematology research is supported across NIH by many of its 27 institutes and centers, including the National Heart, Lung and Blood Institute (NHLBI), the National Cancer Institute, and the National Institute of Diabetes, Digestive and Kidney Diseases. This work is essential to advancing our understanding and treatment of blood disorders and improving patient outcomes.

Few treatments are available to help individuals with SCD manage the pain crises associated with this genetic disease. Prior to the 2023 approval of two gene therapies, a blood and bone marrow transplant was the only curative option. Research conducted by NHLBI and the National Human Genome Research Institute played a critical role in developing these two groundbreaking gene therapies offering patients a new curative option. Additionally, CAR-T therapy, first approved for children with acute lymphoblastic leukemia (ALL) and certain adults with large B-cell lymphoma, has provided a vital treatment option for individuals with relapsed or treatment-resistant cancers. The first child with ALL was treated with CAR-T at the NIH Clinical Center in 2012, with NIH support helping to advance the clinical trials that made this therapy a reality. These innovations are changing the practice of classical and malignant hematology (and many other areas of medicine), and the *ASH Agenda for Hematology Research* highlights key emerging and transformative areas of research that will launch the field into the next generation of therapies for hematologic conditions.[1]

ASH thanks Congress for the past bipartisan support that resulted in nearly a decade of welcome and much needed funding increases for NIH. Robust support for medical research makes Americans healthier. Patients across the country -- from urban centers to rural communities -- benefit from medical research supported by the NIH. Each year, more than 300,000 researchers across labs and other settings in nearly every congressional district nationwide[2,3] conduct research on the most promising strategies to promote patient well-being and overcome existing and emerging health threats, including cancer, Alzheimer's disease and related dementias, diabetes, Parkinson's, chronic health conditions, and the full range of other diagnoses that patients, families, and communities face every day. Underfunding NIH will result in fewer clinical trials, less fundamental discovery research, slower progress delivering new innovations and life-saving advances, and erosion of U.S. leadership in biomedical research.

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[1]ASH Agenda for Hematology Research. *https://www.hematology.org/research/ash-agenda-for-hematology-research*. Accessed April 1, 2025.
[2] National Institutes of Health. Impact of NIH Research; Direct Economic Contributions. *https://www.nih.gov/about-nih/what-we-do/impact-nih-research/serving-society/direct-economic-contributions*. Accessed February 5, 2025.
[3] Federation of American Societies for Experimental Biology. Federal Research Funding Date. *https://www.faseb.org/science-policy-and-advocacy/federal-funding-data*. Accessed March 7, 2025.

For FY 2026, ASH joins over 500 organizations and institutions across the NIH stakeholder community to strongly support the Ad Hoc Group for Medical Research recommendation that NIH receive at least $51.303 billion for its foundational work, which would represent a $4.2 billion or 9% increase over the current funding level. This investment would allow NIH's base budget to keep pace with the biomedical research and development price index (BRDPI) and allow meaningful growth of roughly five percent.

Centers for Disease Control and Prevention

The Society also recognizes the significant role of the CDC and its critical work on preventing and controlling clotting disorders such as venous thromboembolism, reducing complications from bleeding disorders such as hemophilia, and improving the care and treatment of individuals with SCD. ASH is deeply concerned that the entire staff of CDC's Division of Blood Disorders and Public Health Genomics (DBDPHG) was placed on administrative leave and we are worried about the impact this will have on CDC's work on-related conditions, including SCD. No other federal agency or private entity can substitute for the expertise, technical assistance, data, and research that CDC provides to jurisdictions and partners.

SCD is an inherited, lifelong disorder affecting approximately 100,000 Americans. Individuals with the disease produce abnormal hemoglobin which results in their red blood cells becoming rigid and sickle-shaped, causing them to get stuck in blood vessels and block blood and oxygen flow to the body, which can cause severe pain, stroke, organ damage, and in some cases premature death. Though new approaches to managing SCD have led to improvements in diagnosis and supportive care, many people living with the disease are unable to access quality care and are limited by a lack of effective treatment options.

The Sickle Cell Data Collection program awards grants to states, academic institutions, and non-profit organizations to study long-term trends in diagnosis, treatment, and healthcare access for people with SCD in the U.S. Currently, 16 states participate in the data collection program, with data being collected from multiple sources (e.g., newborn screening programs and Medicaid) to create individual health care utilizations profiles. Funding through the CDC Foundation has allowed Georgia and California to collect data since 2015; additional CDC Foundation funding, along with discretionary funding from CDC and HHS, and funding provided by Congress, has allowed fourteen additional states (Alabama, Arizona, Colorado, Florida, Indiana, Michigan, Minnesota, Missouri, New Jersey, North Carolina, Rhode Island, Tennessee, Texas, and Wisconsin) to begin their data collection programs. These 16 states are estimated to include roughly 50 percent of the U.S. SCD population.

ASH thanks Congress for the $6 million provided for the data collection program in FY 2024 and FY 2025. This funding will allow the program to maintain its current level of support in states currently participating in the program. However, the Society strongly recommends providing the Sickle Cell Data Collection program with at least $10 million in FY 2026. This additional funding will allow the program to continue in the states currently participating and also to expand the program to include additional states, with the goal of covering the majority of the U.S. An increase in funding would also provide the program with the opportunity to leverage lessons learned through CDC's data modernization efforts to help improve technical aspects of the program and provide for more coordinated and timely data analysis.

Additionally, ASH supports the public health community's request for at least $11.581 billion in overall funding for the CDC in FY 2026. Strong funding for CDC is vital to supporting all of CDC's activities and programs, which are essential to protect the health of our communities.

Report Language

ASH also supports the inclusion of report language related to sickle cell trait (SCT) within the report accompanying the FY 2026 Labor-HHS appropriations bill. SCT occurs when a person carries a single gene for SCD. SCT is more common among people whose ancestors come from Africa, the Mediterranean region, Middle East, and South Asia, but anyone can have SCT. One to three million Americans are estimated to have SCT, including about one in 13 Black or African American babies born in the United States. SCT is not a mild form of SCD; individuals with SCT do not have SCD at birth, nor will they develop SCD later in life. Having SCT simply means that a person carries a single gene for SCD and can pass this gene along to their children. People with SCT usually do not have any of the symptoms of SCD and live a normal life. However, there are rare cases in which SCT is connected to extreme medical issues, like renal medullary carcinoma (RMC) and sudden collapse following exercise, and if two individuals with SCT have a child, the child could be born with SCD. For these reasons, it is important for all individuals to know whether they have SCT. While all newborns in the United States are now tested for SCD and SCT, follow-up for those identified as carriers of SCT is inconsistent. Standardizing how positive newborn screening results for SCT are communicated is crucial to ensuring the well-being of these individuals across the lifespan.

Under the Department of Health and Human Services, Office of the Secretary, General Departmental Management, ASH supports the inclusion of the following report language:

> *Sickle Cell Trait (SCT) status is identified at birth through universal newborn screening (NBS) in all 50 States, the District of Columbia, and U.S. territories. Based on screening results, about 1 in 13 Black or African American babies is born with SCT. Currently, there are no standards for States' short- and long-term follow-up practices regarding screening results for those identified as carriers. The Committee encourages the Office of the Secretary to work with relevant federal agencies, including the CDC and the Office of the National Coordinator for Health Information Technology, and States to standardize the communication of NBS data that is positive for SCT to individuals across the lifespan, especially among the Black or African American community. This should include integrating NBS data into patient records and ensuring access to needed support and services for people with SCT, such as follow-up testing, genetic counseling, and education for women of child-bearing age. The Committee also encourages HHS to engage HRSA and other relevant agencies and external stakeholders to develop and implement a public awareness campaign and provider education on SCT.*

The Society thanks you for your consideration of these requests for FY 2026. Please contact ASH Senior Manager, Legislative Advocacy, Tracy Roades at 202-292-0256 or troades@hematology.org, for further information concerning hematology research or ASH's FY 2026 requests.