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American Society of Hematology Statement to the
Senate Appropriations Subcommittee on Labor, HHS, Education, and Related Agencies
FY 2026 Funding for Public Health Agencies and Programs, Including NIH and CDC
June 13, 2025

The American Society of Hematology (ASH) appreciates the opportunity to provide outside witness testimony to the Senate 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.

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 (classical) 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 deep 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 spent as intended. We must not lose the momentum of decades of progress in hematology. Codifying the administration's actions, whether through a recissions package or allowing continued impoundment, harms our public health and undermines Congress' role in the budget and spending processes. Congress must exercise its oversight authority to restore programs which

were legally funded in FY 2024 and FY 2025 through bipartisan consensus and preserve the United States' role as the world leader in cutting-edge research and patient care.

Furthermore, we urge the Appropriations Committee to refrain from including harmful policy riders that serve to reorganize agencies. While ASH and the public health community welcome the opportunity to work with Congress to identify ways to improve the workings of our public health agencies, we encourage these actions to take place as part of comprehensive authorizing legislation that involves ample opportunity for the public to provide input.

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. 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 and Digestive and Kidney Diseases. This work is essential to advancing our understanding and treatment of blood disorders and improving patient outcomes. 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. 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. However, the Society is deeply concerned that the President's FY 2026 budget request, which seeks a funding cut of nearly 40 percent and consolidates or eliminates institutes and centers without congressional hearing or input, would reverse the tremendous support Congress has provided the agency.

NIH-supported research occurs in every state and nearly every congressional district[2] and NIH funding directly and indirectly supports hundreds of thousands of jobs nationwide, including nearly 408,000 jobs supported in FY 2024.[3] Should there be cuts to the NIH, many institutions will no longer be able to afford the costs necessary to perform research or will be forced to significantly scale back their efforts. Across institutions jobs will be lost, laboratories will close, and the research workforce capacity will be cut. Cuts to NIH will result in fewer clinical trials,

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[1]ASH Agenda for Hematology Research. *https://www.hematology.org/research/ash-agenda-for-hematology-research*.
[2] Federation of American Societies for Experimental Biology. Federal Research Funding Data. *https://www.faseb.org/science-policy-and-advocacy/federal-funding-data*.
[3] United for Medical Research. NIH's Role in Sustaining the U.S. Economy. *https://www.unitedformedicalresearch.org/annual-economic-report/*.

less fundamental discovery research, slower progress delivering new innovations and lifesaving advances, and erosion of U.S. leadership in biomedical research.

Recent executive orders and administration policies, as well as the threat of cuts to NIH's budget, are already significantly impacting clinical, translational, and basic research, in addition to clinical care. As of April, NIH had already scaled back new grant awards by $2.3 billion.[4] Delayed grant reviews and reductions in research funding in any area will cause years of damage and prevent patients from seeing the impacts of improved diagnostic and treatment options. Furthermore, the continued uncertainty is threatening both the future research workforce and the job security of Americans across the country, particularly those who provide administrative and laboratory support in research centers. The Society has already heard from hematology researchers from across the nation who have had to layoff lab personnel or whose institutions have instituted hiring freezes. ASH has also heard from members about the devastating ways this tumultuous and uncertain time has already impacted hematology:

- A member at an institution working toward becoming an NCI-Designated Cancer Center noted that the institution is now facing a $12 million dollar funding cut, which will limit opportunities to open clinical trials and keep the institution fully operational.
- A research center in the Midwest has frozen hiring and rescinded offers to PhD researchers. Institutional support for research staff has also stopped, putting responsibility on the principal investigator to support staff or let them go. Researchers are concerned about funding for support staff and are having to focus on what projects have the greatest chance for funding. Lack of funding impacts growth in labs and decreases innovative projects that were in progress.
- An investigator at a multi-site study on transfusion medicine noted that funding was cut for one of the sites. For the study to continue, the other sites had to pick-up the work that the other institution had been doing without any additional funding.
- One researcher noted that grants are being flagged for use of several terms including pregnancy, pregnant people, women, and female, forcing researchers to spend time "policing language" instead of focusing on science. They fear this will further discourage research into women's health, an area where investment is already insufficient to meet the need.
- Questioning the availability of funding in the future, one veteran investigator indicated they are strategically evaluating ongoing projects and making decisions about what projects to sunset and which to continue. All these projects have been well-supported and have yielded impactful publications, but the investigator no longer believes in the sustainability of maintaining a large program (about 15 lab members) and is no longer recruiting new staff or trainees while also working with current lab personnel to focus efforts.

ASH urges the Appropriations Committee to reject any cuts to NIH and, instead, 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.

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[4] *https://www.statnews.com/2025/04/24/trump-100-days-nih-new-grants-cut/#:%7E:text=This%20analysis%20does%20not%20include,clawed%20back%20by%20the%20NIH.*

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 earlier this spring and about the impact this will have on CDC's work on-related conditions, including SCD and, notably, the Sickle Cell Data Collection (SCDC) program. 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 SCDC program is the only national public health surveillance initiative solely focused on individuals living with SCD. This program received its first congressional appropriation in 2019; because of those funds and continued congressional funding – including appropriations of $6 million in FY 2024 and FY 2025 – the program has expanded from two states to 16 states. The program collects, analyzes, and disseminates essential data on SCD prevalence, care patterns, health outcomes, and mortality – data that is not otherwise systematically gathered on a national scale. The data from the SCDC program drives decisions made for federal and state programs including programs providing health services.

The loss – or even temporary disruption – of this program, including termination of staff, will undermine more than a decade of progress in building a national infrastructure for SCD surveillance and will halt all current and new federal, state, and local SCD programs that rely on this data. ASH urges Congress to ensure the continuity of the SCDC program by providing at least $10 million for the program in FY 2026, which will allow the program to continue in the states currently participating and expand to include additional states, with the goal of covering the majority of the U.S.

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.

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.