



**American Society of Hematology Statement to the
Senate Appropriations Subcommittee on Labor, HHS, Education, and Related Agencies
FY 2024 Funding for NIH, CDC, and HRSA
May 18, 2023**

The American Society of Hematology (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.

National Institutes of Health (NIH)

Hematology research, funded by many institutes at the NIH, including the National Heart, Lung and Blood Institute (NHLBI), the National Cancer Institute (NCI), and the National Institute of Diabetes, Digestive and Kidney Diseases (NIDDK), has been an important component of Congress' investment in the nation's health. NIH-funded research has led to tremendous advances in treatments for children and adults with blood cancers and other hematologic diseases and disorders. Hematology advances also help patients with other types of cancers, heart disease, and stroke. Basic research on blood has aided physicians who treat patients with heart disease, strokes, end-stage renal disease, cancer, and AIDS.

The field of hematology continues to evolve and move closer to conquering blood diseases thanks to novel technologies, mechanistic insights, and cutting-edge therapeutic strategies, which would not have been possible without Congress' investment in NIH. Groundbreaking scientific research highlighted at the December 2022 ASH Annual Meeting and Exposition, much of which was either funded by NIH or derived from NIH-funded research, presented information on advances in gene therapy, practice-changing discoveries in immunotherapies, and advances in patient care for a wide range of hematologic diseases and conditions. Moreover, the Society's regularly updated [ASH Agenda for Hematology Research](#) serves as a roadmap to prioritize research within the hematology field and includes recommendations for areas of additional federal investment that will equip researchers to make truly practice-changing discoveries in hematology and other fields of medicine for years to come.

ASH thanks Congress for the robust bipartisan support that has resulted in nearly a decade of welcome and much needed funding increases for NIH. For fiscal year (FY) 2024, ASH joins nearly 400 organizations and institutions across the NIH stakeholder community to strongly support the Ad Hoc Group for Medical Research [recommendation](#) that NIH receive at least \$50.924 billion for its foundational work, a \$3.465 billion increase over the comparable FY 2023 program level, which would allow NIH's base budget to keep pace with the biomedical research and development price index (BRDPI) and allow meaningful growth of nearly five percent.

ASH also joins the community in strongly urging lawmakers to ensure that any funding for the new Advanced Research Projects Agency for Health (ARPA-H) supplement the recommendation for NIH's base budget, rather than supplant the essential foundational investment in the NIH. Continued investment in NIH's basic science and translational research and the resulting

foundation it provides is necessary for ARPA-H to fulfill its promise as a biomedical research accelerator.

Centers for Disease Control and Prevention (CDC)

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. With a close connection between hematology and maternal health, ASH also recommends that the hematologic perspective is included in cross-CDC discussions about maternal health, including how existing programs such as the Sickle Cell Data Collection program could be leveraged to close knowledge gaps related to maternal health.

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.

CDC, through its 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 eleven 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 enabled Georgia and California to collect data since 2015; additional CDC Foundation funding, along with discretionary funding from CDC and the Department of Health and Human Services (HHS) and funding provided by Congress since FY 2021 has expanded data collection programs to include nine additional states (Alabama, Colorado, Indiana, Michigan, Minnesota, North Carolina, Tennessee, Virginia, and Wisconsin). These eleven states are estimated to include just over 35% of the U.S. SCD population.

ASH thanks Congress for the \$6 million provided for the data collection program in FY 2023 and appreciates the administration's request for \$6 million in FY 2024. This funding will allow CDC to maintain its current level of support in states currently participating in the program. However, the Society strongly recommends providing CDC with at least \$10 million in FY 2024 for the Sickle Cell Data Collection program. 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. SCD population over the next five years. An increase in funding would also provide CDC with the opportunity to leverage lessons learned through its 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 2024. 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.

Health Resources and Services Administration (HRSA)

ASH supports funding for the SCD programs within HRSA's Maternal and Child Health Bureau, including \$8.205 million for the SCD Treatment Demonstration Program (SCDTDP) and at least \$7 million for the SCD Newborn Screening Program, which is part of HRSA's Special Projects of Regional and National Significance (SPRANS) program. The grantees funded by these programs work to improve access to quality care for individuals living with SCD and sickle cell trait. The SCDTDP funds five geographically distributed regional SCD grants that support SCD providers to increase access to high quality, coordinated, comprehensive care for people with SCD, while the SCD Newborn Screening Program provides grants to support the comprehensive care for newborns diagnosed with SCD.

Finally, ASH joins many others in the physician community in supporting funding for HRSA's Supporting the Mental Health of the Health Professions Workforce program. Health care professionals have long experienced high levels of stress and burnout, and our members have shared that the COVID-19 pandemic only exacerbated these problems. Burnout has been shown to reduce job performance, increase turnover, and, in its most extreme instances, lead to mental health issues. This important program, authorized as part of provisions in the *Dr. Lorna Breen Health Care Provider Protection Act*, will provide funding to support the implementation of evidenced-based and evidence-informed programs, practices, and trainings with the goal of reducing burnout and promoting mental health and wellness among the health care workforce. ASH supports the administration's request for \$25 million for the Supporting the Mental Health of the Health Professions Workforce program in FY 2024 and respectfully urges Congress to provide this funding in order to expand access to vital programs to address the growing mental health challenges facing our health care workforce.

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 2024 requests.