



**American Society of Hematology
Statement to the Senate Appropriations
Subcommittee on Labor, HHS, Education, and Related Agencies
FY 2023 Funding for NIH, CDC, and HRSA
May 11, 2022**

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), the National Institute of Diabetes, Digestive and Kidney Diseases (NIDDK), the National Institute on Aging (NIA), and the National Institute of Allergy and Infectious Diseases (NIAID), has been an important component of this 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 make great strides in conquering blood diseases thanks to novel technologies, mechanistic insights, and cutting-edge therapeutic strategies. Groundbreaking scientific research highlighted at the December 2021 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.

Additionally, extraordinary research that has occurred over the past two years to identify and develop COVID-19 vaccines, antivirals, and other medical countermeasures is all built on the scientific foundation enabled by the federal investment in NIH. In response to the emergence of significant hematologic complications from COVID-19 infection, ASH developed the [ASH COVID-19 Research Agenda in Hematology](#), which highlights fundamental questions that experts in hematology and blood research deem of critical importance to researchers, physicians, and patients. The questions outlined in the document identify significant questions about the biology, pathophysiology, and underlying clinical implications of COVID-19 as they relate to hematology science and clinical care and are meant to inspire research that leads to enhanced understanding of the disease process, decreased hematologic complications in COVID-19, and improved care of patients with hematologic disease. The original document outlined hematology-

related basic science and clinical research questions that emerged in the first few months of the pandemic; the research agenda continues to be updated as our understanding of the natural history and treatment of COVID-19 improves.

ASH thanks Congress for the robust bipartisan support that has resulted in seven consecutive years of welcome and much needed funding increases for NIH. For fiscal year (FY) 2023, 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 a program level of at least \$49.048 billion. This funding level would allow for meaningful growth above inflation in the base budget that would expand NIH's capacity to support promising science in all disciplines. 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 \$49 billion recommendation for NIH's base budget, rather than supplant the essential foundational investment in the NIH. In addition, ASH supports the Administration's proposal to supplement NIH's budget with additional mandatory funding to speed the pace of pandemic response and readiness.

Centers for Disease Control and Prevention (CDC)

The Society also recognizes the important role of the CDC in preventing and controlling clotting, bleeding, and other hematologic disorders. This is especially important for improving the care and treatment of individuals with sickle cell disease (SCD).

Sickle cell disease 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 Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act of 2018* (P.L. 115—327) authorized CDC, through its Sickle Cell Data Collection program, to award grants to states, academic institutions, and non-profit organizations to gather information on the prevalence of SCD and health outcomes, complications, and treatment that people with SCD experience. Currently eleven states participate in the data collection program, with data being collected from multiple sources (e.g., newborn screening programs and Medicaid) in order to create individual health care utilization 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 the Department of Health and Human Services (HHS) and \$2 million in funding provided by Congress in FY 2021 has allowed nine additional states (Alabama, Colorado, Indiana, Michigan, Minnesota, North Carolina, Tennessee, Virginia, and Wisconsin) to begin their data collection programs. These eleven states are estimated to include just over 35% of the U.S. SCD population.

ASH thanks Congress for the \$3 million provided for the data collection program in FY 2022. This funding will allow CDC to continue to support data collection efforts in all of the states currently participating in the program. ASH also appreciates the Administration's request for \$4.5 million in funding for the program in FY 2023. However, the Society strongly supports providing CDC with at least \$10 million in FY 2023 for the Sickle Cell Data Collection program. This additional funding is necessary to allow the program to continue in the states currently participating in the programs and to also expand the programs to include additional states with the goal of covering the majority of the U.S. SCD population over the next five years.

To further support CDC's sickle cell data collection efforts, ASH urges the inclusion of the following report language under CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD):

- *Public Health Approach to Blood Disorders/Sickle Cell Disease*
The Committee includes \$10,000,000 for the Sickle Cell Data Collection program to allow for data collection and analysis in states currently participating in the program and to allow for expansion to additional states. The Committee encourages CDC to provide technical assistance to additional states with a higher prevalence of SCD, so that they can successfully participate in this grant program to better identify affected individuals in their states and better meet their needs.

Additionally, ASH supports the public health community's request for at least \$11 billion in overall funding for the CDC in FY 2023. Strong funding for CDC is critical to supporting all of CDC's activities and programs, which are essential to protect the health of our communities. In addition to ensuring a strong public health infrastructure and protecting our communities from public health threats and emergencies, CDC programs are crucial to reducing health care costs and improving health. However, due to years of underfunding, many CDC programs have not received the resources that are needed to address the many health challenges we face as a nation. A funding level of at least \$11 billion would build upon the funding increase Congress provided CDC in FY 2022 and strengthen all of CDC's programs.

Health Resources and Services Administration (HRSA)

ASH supports funding for the SCD programs within HRSA's Maternal and Child Health Bureau, including \$9.205 million for the SCD Treatment Demonstration Program (SCDTDP) and at least \$6 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. ASH also supports the inclusion of language in the report accompanying the FY 2023 appropriations bill recognizing the importance of the Sickle Cell Disease Treatment Demonstration Program in supporting the growth of comprehensive sickle cell disease centers:

- *Sickle Cell Disease Treatment Demonstration Program*

The Committee includes \$9,205,000 for this program, a \$2,000,000 increase above the fiscal year 2022 enacted level. The Committee recognizes the importance of the program in supporting the comprehensive sickle cell disease (SCD) centers in the provision of coordinated, comprehensive, culturally competent, and family-centered care to people with SCD. The Committee affirms the goals of the program to improve care delivery and access to high quality care for people with SCD, with a focus on increasing access to SCD specialists; increase the number of providers with SCD expertise and knowledge of SCD treatment methods; and enable access to the latest treatment options following evidence-based guidelines

Finally, ASH joins many others in the physician community in supporting funding for HRSA's Preventing Burnout in the Health Workforce program. Health care professionals have long experienced high levels of stress and burnout, and our members have shared that COVID-19 has only exacerbated the problem. Burnout has been shown to reduce job performance, increase turnover, and, in its most extreme instances, lead to mental health issues. This important program, established by the *American Rescue Plan Act* and modeled after provisions in the *Dr. Lorna Breen Health Care Provider Protection Act*, provides grants to health care organizations to support 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. As the U.S. continues to deal with the COVID-19 crisis, ASH respectfully urges Congress to provide robust funding for the Preventing Burnout in the Health Workforce program in order to expand access to vital programs to address the growing mental health challenges facing our health care workforce.

Thank you again for the opportunity to submit testimony. Please contact ASH Senior Manager, Legislative Advocacy, Tracy Roades at 202-292-0256 or troades@hematology.org, if you have any questions or need further information concerning hematology research or ASH's FY 2023 requests.