



**American Society of Hematology
Statement to the House Appropriations
Subcommittee on Labor, HHS, Education, and Related Agencies
FY 2022 Funding for NIH, CDC, and HRSA
May 19, 2021**

The American Society of Hematology (ASH) represents more than 17,000 clinicians and scientists committed to the study and treatment of blood and blood-related diseases, including malignant disorders such as leukemia, lymphoma, and myeloma; conditions including thrombosis and bleeding disorders; and congenital diseases such as sickle cell disease, thalassemia, and hemophilia.

FY 2022 Request: National Institutes of Health (NIH)

American biomedical research has led to new medical treatments, saved innumerable lives, reduced human suffering, and spawned entire new industries, none of which would have been possible without support from the 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 Society recently updated the [ASH Agenda for Hematology Research](#), which 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, the extraordinary research that has occurred to identify and develop potential 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 hematologic complications from COVID-19 infection, ASH developed the [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.

ASH thanks Congress for the robust bipartisan support that has resulted in several consecutive years of welcome and much needed funding increases for NIH. For FY 2022, 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 \$46.1 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.

While we are grateful for Congress's ongoing commitment to NIH as a top national priority through the regular appropriations process, we also urge the inclusion of emergency supplemental investments for the NIH as Congress considers future legislation to promote the nation's physical, health, and economic resilience to the COVID-19 pandemic.

The pandemic's impact on biomedical research has been serious and far-reaching. Researchers in every state were forced to suspend many laboratory activities for their own personal safety and to comply with physical distancing guidelines. The closure of many research facilities impacted trainees, technicians, early-stage investigators, and established investigators alike, preventing the research workforce from maintaining momentum toward better prevention, treatments, diagnostics, and cures for diseases such as blood cancers, sickle cell disease, and other hematologic diseases and conditions. While many institutions have been implementing plans to ramp this work back up again as safely as possible, challenges associated with the disruptions continue to linger. For example, certain types of research – such as clinical trials and other research projects with human participants – have been slower to recover. Additionally, as a result of the lags, we risk undoing progress we have made in recent years in strengthening the research workforce, including among women, underrepresented minorities, and early-career investigators and others at a pivotal point in their career trajectories.

To enable NIH to mitigate the pandemic-related disruptions without foregoing promising new science, ASH strongly supports emergency funding for federal research agencies as outlined in the bipartisan Research Investment to Spark the Economy (RISE) Act (H.R. 869/S. 289), including \$10 billion for NIH.

FY 2022 Request: 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. Funding through the CDC Foundation has allowed Georgia and California to collect data since 2015; seven additional states (Alabama, Indiana, Michigan, Minnesota, North Carolina, Tennessee, and Wisconsin) were able to begin their programs in FY 2021 with the \$2 million in funding provided by Congress in the FY 2021 Consolidated Appropriations Act. In early March 2021, the program expanded to Colorado and Virginia with additional funding from the CDC Foundation. These eleven states are estimated to include just over 35% of the U.S. SCD population.

ASH thanks Congress for the \$2 million provided for the data collection program in FY 2021.

The Society strongly supports providing CDC with at least \$5 million in FY 2022 to continue to phase in the data collection program in the currently participating states and to allow for an expansion to additional states with the goal of covering the majority of the U.S. SCD population over the next five years.

FY 2021 Request: Health Resources and Services Administration (HRSA)

Finally, ASH supports maintaining funding for the SCD programs within HRSA's Maternal and Child Health Bureau, including the SCD Treatment Demonstration Program (SCDTDP) and SCD Newborn Screening 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 2022 appropriations bill asking HRSA to provide Congress with a report detailing how the Sickle Cell Disease Treatment Demonstration Program is supporting the growth of comprehensive sickle cell disease centers.

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 2022 requests.