AMERICAN SOCIETY OF HEMATOLOGY
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American Society of Hematology
Statement to the House Appropriations
Subcommittee on Labor, HHS, Education, and Related Agencies
FY 2023 Funding for NIH, CDC, and HRSA
May 26, 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.

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 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 sickle cell disease (SCD).

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 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 study long-term trends in diagnosis, treatment, and healthcare access for people with SCD in the United States. 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 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 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.

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 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 $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.

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.