## 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

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Exposition, much of which was either funded by NIH or derived from NIH-funded research,

presented information on advances in gene therapy

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

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 <u>troades@hematology.org</u>, if you have any questions or need further information concerning hematology research or ASH's FY 2023 requests.