



**American Society of Hematology
Statement to the House Appropriations Subcommittee on Labor, HHS, Education, and
Related Agencies
FY 2018 Funding for NIH and CDC
March 8, 2017**

ASH represents more than 17,000 clinicians and scientists committed to the study and treatment of blood and blood-related diseases. These diseases encompass malignant disorders such as leukemia, lymphoma, and myeloma; life-threatening conditions, including thrombosis and bleeding disorders; and congenital diseases such as sickle cell anemia, thalassemia, and hemophilia. In addition, hematologists have been pioneers in the fields of bone marrow transplantation, stem cell biology and regenerative medicine, gene- and immunotherapy, and the development of many drugs for the prevention and treatment of heart attacks and strokes.

FY 2018 Request: NIH Funding

ASH thanks Congress for the robust bipartisan support that resulted in the welcome and much needed funding increase for the National Institutes of Health (NIH) that Congress provided in the FY 2016 Consolidated Appropriations Act as well as the additional funding provided for NIH in the 21st Century Cures Act that was passed and signed into law in December 2016. For FY 2018, ASH strongly supports the Ad Hoc Group for Medical Research recommendation that NIH receive at least \$2 billion above the final FY 2017 funding level, in addition to funds included in the 21st Century Cures Act for targeted initiatives. This funding level would enable real growth over biomedical inflation as an important step to ensuring stability in the nation's research capacity over the long term. Moreover, this recommendation would help advance the scientific momentum envisioned by the 21st Century Cures Act – enacted with broad bipartisan support – in which the Innovation Account supplements the agency's base budget. Securing a reliable,

robust budget trajectory for NIH will be key in positioning the agency to capitalize on the full range of research in the biomedical, behavioral, social, and population-based sciences.

Over the past 60 years, American biomedical research has led the world in probing the nature of human disease. This 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 NIH. Funding for hematology research has been an important component of this investment in the nation's health. The study of blood and its disorders is a trans-NIH issue involving 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), and the National Institute on Aging (NIA).

With the advances gained through an increasingly sophisticated understanding of how the blood system functions, hematologists have changed the face of medicine through their dedication to improving the lives of patients. As a result, children are routinely cured of acute lymphoblastic leukemia (ALL); more than 90 percent of patients with acute promyelocytic leukemia (APL) are cured with a drug derived from vitamin A; older patients suffering from previously lethal chronic myeloid leukemia (CML) are now effectively treated with well-tolerated pills; and patients with multiple myeloma are treated with new classes of drugs.

Hematology advances also help patients with other types of cancers, heart disease, and stroke. Even modest investments in hematology research have yielded large dividends for other disciplines. Basic research on blood has aided physicians who treat patients with heart disease,

strokes, end-stage renal disease, cancer, and AIDS. Blood thinners effectively treat or prevent blood clots, pulmonary embolism, and strokes. Death rates from heart attacks are reduced by new forms of anticoagulation drugs.

The field of hematology has experienced a recent surge in progress thanks to novel technologies, mechanistic insights, and cutting-edge therapeutic strategies that have driven significant and meaningful advances in the quality of care. Insights into new genetic and biologic markers can be used to understand what causes a disease, the risk factors that predispose to disease, and how patients will respond to a particular treatment. These foundational insights are reframing modern research with the continued goal of improving outcomes and discovering cures for the most challenging hematologic diseases.

ASH has created several videos highlighting the progress made, and the future promise, in areas such as genomic profiling (available on YouTube at: <https://www.youtube.com/watch?v=-KwPGr7MEqU&t=44s>) and the treatment of venous thromboembolism (available on YouTube at: https://www.youtube.com/watch?v=KjGtiKgf_U4).

FY 2018 Request: Centers for Disease Control and Prevention (CDC)

The Society also recognizes the important role of the Centers for Disease Control and Prevention (CDC) in preventing and controlling clotting, bleeding, and other hematologic disorders.

Sickle cell disease (SCD) is an inherited, lifelong disorder affecting nearly 100,000 Americans. Individuals with the disease produce abnormal hemoglobin which results in their red blood cells

becoming rigid and sickle-shaped and causing them to get stuck in blood vessels and block blood and oxygen flow to the body. SCD complications include severe pain, stroke, acute chest syndrome (a condition that lowers the level of oxygen in the blood), 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.

Surveillance is necessary to improve understanding of the health outcomes and health care system utilization patterns, increase evidence for public health programs and to establish cost-effective practices to improve and extend the lives of people with SCD. With funding from the CDC Foundation, CDC has established a population-based surveillance system to collect and analyze longitudinal data about people living in the U.S. with SCD. Data is being collected from multiple sources (newborn screening programs and Medicaid) in order to create individual healthcare utilization profiles. However, due to limited funding, implementation of the program has occurred only in two states – California and Georgia (approximately 10% of the U.S. SCD population).

CDC's SCD Surveillance Program should be maintained and expanded to include additional states with the goal of covering the majority of the US SCD population over the next 5 years. For FY 2018, the Society urges the Subcommittee to provide dedicated funding for SCD surveillance, outreach, and education programs to the CDC's Blood Disorders Division within the National Center on Birth Defects and Developmental Disabilities. Funding is needed for coordination and implementation of a training curriculum in the states with large SCD

populations. CDC should develop a comprehensive, national public health awareness campaign for people with SCD and sickle cell trait (SCT, when a person carries a single gene for sickle cell disease and can pass this gene along to their children), their families, and the general public along with an educational campaign for the medical professionals who provide health care for people living with SCD or SCT. The goals of this effort would be to improve overall awareness of SCD and SCT and knowledge about health outcomes and understanding of the implications for family planning and to provide educational tools for healthcare professionals to help them understand the effects of medical interventions and inform best practices for SCD.

Additionally, ASH is supportive of the Public Health and Prevention Fund which has supported many critical projects at CDC, including investments in health-care associated infections. Currently the fund comprises approximately 12 percent of CDC's budget. ASH is concerned about the proposed elimination of this fund as part of the ACA repeal bill because of the budgetary pressure this would place on other programs within the Subcommittee's jurisdiction.

Thank you again for the opportunity to submit testimony. Please contact Tracy Roades, ASH Legislative Advocacy Manager, at 202-776-0544 or troades@hematology.org, if you have any questions or need further information concerning hematology research or ASH's FY 2018 requests.