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The Honorable Xavier Becerra Secretary U.S. Department of Health and Human Services 200 Independence Avenue SW Washington DC 20201

Dear Secretary Becerra:

I am writing on behalf of the American Society of Hematology (ASH) to congratulate you on being sworn in as Secretary of the U.S. Department of Health and Human Services (HHS) and to offer the Society's expertise as a resource to you. ASH welcomes the opportunity to work with the Biden Administration to address the many public health challenges that face our nation - from rare diseases such as blood cancers and sickle cell disease, to epidemics like COVID-19 that impact our patients, to health inequities and systemic racism that have prevented far too many individuals from accessing quality health care. We stand ready to assist and request a virtual meeting with you to provide a briefing on these very pressing issues.

ASH represents over 17,000 clinicians and scientists worldwide who are committed to the study and treatment of blood and blood-related diseases. These disorders encompass malignant hematologic disorders such as leukemia, lymphoma, and multiple myeloma, as well as non-malignant conditions such as sickle cell disease, thalassemia, bone marrow failure, venous thromboembolism, and hemophilia. In addition, hematologists were pioneers in demonstrating the potential of treating various hematologic diseases through the transplantation of bone marrow stem cells, and we continue to be innovators in the fields of stem cell biology, regenerative medicine, transfusion medicine, and gene therapy. ASH membership is comprised of basic, translational, and clinical scientists, as well as physicians who are providing care to patients in diverse settings including teaching and community hospitals, as well as private practices.

The field of hematology continues to make great strides in conquering blood diseases thanks to novel technologies, mechanistic insights, and cutting-edge therapeutic strategies. We are at an especially exciting time as we are on the heels of the 2020 ASH Annual Meeting and Exposition, which highlighted groundbreaking scientific research, from advances in gene therapy to practice-changing discoveries in immunotherapies, as well as the latest advances in patient care and attention to racial disparities in science and practice. Additionally, the Society recently released updates to the ASH Agenda for Hematology Research that serves as a roadmap for the prioritization of research across the hematology community.

ASH is also strongly committed to combating inequities in health care, with a particular focus in hematology, supporting scientists and clinicians from backgrounds underrepresented in medicine, and embracing diverse voices across the patient and health care communities. As a global hematology community, we appreciate the importance of having individuals with diverse perspectives and experiences in all areas of the field. The Society also continues to advocate for policies and support programs that aim to eliminate health disparities in the care of hematology patients, including those with sickle cell disease and blood cancers.

I have attached a brief document outlining the Society's top policy priorities and look forward

to the opportunity to discuss these in more detail when we meet. In the meantime, please feel free to contact ASH Chief Policy Officer, Suzanne Leous, MPA at <u>sleons@hematology.org</u> or 202-412-7531 (cell) or Stephanie Kaplan, ASH Deputy Director of Government Relations and Public Health at <u>skaplan@hematology.org</u> or 202-538-3018 (cell) as your points of contact.

Sincerely,

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Martin S. Tallman, MD President

Attachment

cc: Rachel Levine, MD, Assistant Secretary for Health

RADM Felicia Collins, MD, MPH, FAAP, Acting Assistant Secretary for Health Vivek Murthy, MD, MBA, U.S. Surgeon General

ASH Policy Priorities

The American Society of Hematology (ASH) is the leader in representing the interests of scientists and clinicians working in the field of hematology within federal agencies and on Capitol Hill. ASH is committed to combating inequities in hematology care, supporting scientists and clinicians from backgrounds underrepresented in medicine, and embracing diverse voices across the patient and health care communities. The Society is pleased to serve as a resource on hematologic issues and is focused on advancing the policy priorities outlined below.

- Sickle Cell Disease Enhancing and expanding government activities in Sickle Cell Disease (SCD) research, training, and services is a major focus for ASH. During the 115th Congress, ASH worked to pass the Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act, which was signed into law in December 2018. A key provision of this legislation authorizes the federal government to award data collection grants to states, academic institutions, and non-profit organizations with the goal of better understanding the prevalence of SCD and associated complications of this disorder. Funding provided through the annual appropriations process is essential to the ability of the Centers for Disease Control and Prevention (CDC) to issue grants associated with this program. ASH is working with SCD champions on Capitol Hill to introduce legislation that would authorize the Centers for Medicare and Medicaid Services (CMS) to develop a Medicaid demonstration project to improve access to state-of-the-art, high quality outpatient care for individuals living with SCD with a focus on young adults. ASH also works with the Department of Health and Human Resources (HHS) to strengthen its Interagency Working Group on SCD within the Office of the Assistant Secretary for Health so that coordination and synchronization of SCD activities among federal agencies and programs occurs.
- Patient Access to Care High drug prices are a major issue facing patients with hematologic conditions as many of these diseases and disorders are rare and treatments are limited and ASH advocates for patient access to safe, affordable, and effective hematologic drugs. Over the past several years, ASH has advocated for legislation to ensure that cancer patients have equal insurance coverage and access to all approved anticancer regimens including, but not limited to oral and intravenous drugs. ASH also advocates for legislation to significantly limit how much consumers pay for specialty prescription drugs (including biologics and other drugs for diseases and conditions such as cancer and anemia) by requiring a fixed copay (instead of coinsurance) for drugs covered under an insurance plan's prescription drug benefit. Additionally, ASH works closely with the Food and Drug Administration (FDA) on addressing safety and supply issues, partners with the Agency to provide educational programs on hematologic discoveries, and supports improvements in clinical trial design and opportunities to leverage, generate and evaluate real world evidence.
- Medical Research and Public Health Funding ASH advocates for federal support of biomedical research and public health funding, including funding for the National Institutes of Health (NIH) and the CDC. Much of the research that has produced cures and treatments for hematologic diseases, including blood cancers, has been funded by the NIH and sustained and predictable funding for NIH is necessary for important research into new cures and treatments to continue. The Society has developed the <u>ASH Agenda for Hematology Research</u> to serve as a roadmap for the prioritization of research support across the hematology community, including recommendations for dedicated resources that will equip researchers today and in the future to make truly practice-changing discoveries. Meanwhile, CDC's programs are crucial to ensuring a strong public health infrastructure, protecting Americans from public health threats and emergencies, reducing health care costs and improving overall health. The Society supports strong annual appropriations for these agencies as well as supplemental funding for efforts related to the COVID-19 pandemic. ASH also continues to work with members of the scientific, academic, and patient communities to address the restrictions on research involving the use of human fetal tissue that were announced by HHS in June 2019.
- Reimbursement and Coverage ASH regularly comments on numerous proposed rules and regulations issued by CMS that impact physician reimbursement and patient access to care, including the Physician Fee Schedule, Hospital Outpatient Prospective Payment System, and Inpatient Prospective Payment System. Adequate coverage and reimbursement for Chimeric Antigen Receptor (CAR) T-cell Immunotherapy and for future cell and gene therapies is a policy priority for the Society. Additionally, ASH was pleased with the implementation of the changes to the documentation and valuation of the evaluation and management (E/M) services included in the 2021 Physician Fee Schedule final rule that went into effect this past January. ASH has long advocated for better recognition of the cognitive services performed by hematologists.