



AMERICAN SOCIETY OF HEMATOLOGY

2021 L Street, NW, Suite 900, Washington, DC 20036-4929 **ph** 202.776.0544 **fax** 202.776.0545 **e-mail** ASH@hematology.org

December 19, 2024

2025

President

Belinda Avalos, MD
Atrium Health Levine Cancer Institute
1021 Morehead Medical Drive
Building I, Suite 3000
Charlotte, NC 28204
Phone: 980-442-2000

President-Elect

Robert Negrin, MD
Stanford University
CCSR Building, Room 2205
269 W. Campus Drive
Stanford, CA 94305
Phone: 650-723-0822

Vice President

Cynthia Dunbar, MD
NHLBI/NIH
Translational Stem Cell Biology Branch
Building 10-CRC, Room 5E-3332
10 Center Drive
Bethesda, MD 20892
Phone: 301-402-1363

Secretary

Jennifer Brown, MD, PhD
Dana-Farber Cancer Institute
450 Brookline Avenue
Boston, MA 02215
Phone: 617-632-5847

Treasurer

Joseph Mikhael, MD, FRCPC, MEd
Translational Genomics Research Institute
City of Hope Cancer Center
445 N. Fifth Street
Phoenix, AZ 85004
Phone: 602-343-8445

Councillors

Jennifer Holter-Chakrabarty, MD
Chancellor Donald, MD
Christopher Flowers, MD, MS
H. Leighton Grimes, PhD
Mary Horowitz, MD
Charlotte Niemeyer, MD
Sarah O'Brien, MD, MSc
Wendy Stock, MD

Executive Director

Martha Liggett, Esq.

President-Elect Donald J. Trump
Vice President-Elect James D. Vance
c/o Linda McMahon and Howard Lutnick, Co-Chairs
President-elect Donald J. Trump's Transition Team
Washington, DC

Dear President-Elect Trump and Vice President-Elect Vance,

The American Society of Hematology (ASH) congratulates you on your election and the start of this important transition period. As you lay the groundwork for your Administration, ASH looks forward to collaborating on the following key health priorities.

- [Sickle Cell Disease](#)
 - [Comprehensive and Coordinated Care](#)
 - [Federal Data Collection](#)
- [Advancing Biomedical Research](#)
- [Access to High-Quality Care for Patients](#)
 - [Drug Shortages](#)
 - [Maternal Health](#)
- [Physician Payment Reform](#)
- [Access to Innovative Therapies](#)
- [Prior Authorization](#)
- [Telehealth](#)

ASH represents more than 18,000 clinicians and scientists worldwide committed to studying and treating blood and blood-related diseases. These chronic disorders encompass malignant hematologic disorders such as leukemia, lymphoma, and multiple myeloma, as well as classical (or non-malignant) conditions such as sickle cell disease (SCD), thalassemia, bone marrow failure, venous thromboembolism (VTE), and hemophilia. Hematologists have been pioneers in advancing understanding and treatment of various hematologic diseases. Hematologists 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 providing care to patients. Our mission is to foster high-quality care, transformative research, and innovative education to improve the lives of patients with blood and bone marrow disorders.

Most of the conditions our members treat are chronic, and we believe that there is an opportunity to work together to improve the lives of Americans with hematologic disorders. As such, we thank you for your consideration of the following policy recommendations and look forward to working with you.

Sickle Cell Disease

ASH urges you to consider the following issues to continue to support progress for individuals with SCD. Affecting approximately 100,000 Americans, SCD is an inherited, lifelong disorder, which results in patients' red blood cells becoming rigid and sickle shaped. Sick cells can get stuck in blood vessels and block blood flow, causing pain and organ infarctions. Patients with SCD are also at increased risk of infection from certain types of bacteria.

The worst complications include stroke, acute chest syndrome (a condition that lowers the level of oxygen in the blood), organ damage, other disabilities, and premature death. Therefore, it is important for people with SCD to have access to the range of treatment options currently available.

ASH appreciates the efforts your first Administration took to systematically address the challenges individuals living with SCD face, including commissioning the National Academies of Sciences, Engineering, and Medicine (NASEM) report on [Addressing Sickle Cell Disease: A Strategic Plan and Blueprint for Action](#), and hosting the [First Lady's 2020 Roundtable on Improving the Lives of Americans Living with SCD](#). These efforts created a foundation for additional federal investment and programs to meaningfully improve health outcomes, which we encourage you to continue to build upon.

Comprehensive and Coordinated Care

Today, many people with SCD face barriers accessing experienced care teams and therapies, and receive uncoordinated care outside of a medical home, leading to poor clinical outcomes, avoidable complications, low quality of life, and increased costs to the healthcare system. While individuals with SCD are living longer, it is imperative that policies be enacted to improve the care they receive and their quality of life. While the population living with this chronic disorder is small, improvements to the care they receive have the potential to reduce the cost of their care significantly. At the University of Virginia, “a small cohort of individuals with sickle cell disease were identified as a high utilizer population who accounted for 7% of all readmissions to the general medicine services and nearly \$1 million in annual costs.”¹ In response, a multidisciplinary team developed individualized care plans for this small group of patients. These care plans were made available in the electronic medical record to inpatient, outpatient, and emergency department providers. In the four quarters after the intervention, “total costs were reduced by 24% from \$949,935 to \$717,226.”

ASH proudly supports the *Sickle Cell Disease Comprehensive Care Act of 2024*, a bill that authorizes state Medicaid programs to provide comprehensive, coordinated care through a health home model for individuals based on their SCD status alone. Health homes for SCD will help to alleviate the many challenges and disparities in care that individuals with SCD have faced for far too long. This bill provides a multi-faceted approach to care, ensuring SCD patients have access to coordinated clinical, mental health, and ancillary services to address their needs. In addition to improving care, the bill would save money in the Medicaid program, which covers over 50% of individuals with SCD, due to reduced costs associated with lower healthcare utilization.

Recommendation: ASH urges your Administration to support this legislation and other policies to improve care coordination for SCD patients.

Federal Data Collection

Despite the relatively small number of individuals living with SCD, the healthcare system does not have a coordinated method to capture the data necessary to address the complex health challenges these individuals face. There is no mechanism to address programmatic redundancies, share lessons learned, and minimize the capture burden for clinicians, researchers, and patients. NASEM recommended that the U.S. Department of Health and Human Services (HHS) “establish a working group to identify existing and disparate sources of data that can be immediately linked and mined.”² Despite this recommendation, more must still be done to coordinate data collection.

Our Society has made tremendous investments to address the burden of SCD, which include supporting efforts to advance data and research. The [ASH Research Collaborative](#) (ASH RC), founded by ASH in 2018, was established to improve the lives of individuals with blood diseases by fostering collaborative partnerships to accelerate progress in hematology. Specifically, the ASH RC SCD Data Hub, collects real world data that is used for research and to support clinical practice and patient outcomes. Participating health systems and hospitals submit electronic health record (EHR) data for patients with SCD and the data is used to support primary investigators’ research topics and site benchmark reporting.

The Centers for Disease Control and Prevention’s (CDC) [Sickle Cell Data Collection Program](#) has been critical in collecting and analyzing longitudinal data about people living in the U.S. with SCD. Through the program, the CDC awards SCD data collection 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, sixteen states participate in the data collection program, with data being collected from multiple sources to create individual health care utilization profiles. Support for this program is essential to help strengthen and expand the program's current efforts, which will help enable individuals living with this disease to receive adequate care and treatment. Additional support is necessary to allow the program to expand to include additional states with the goal of covering the majority of the U.S. SCD population over the next five years.

Additionally, the Assistant Secretary for Technology Policy / Office of the National Coordinator for Health Information Technology is creating a SCD minimum core dataset under the United States Core Data for Interoperability Plus ([USCDI+](#)) program. The USCDI+ SCD project intends to establish minimum core data elements and definitions that can be implemented within certified EHR systems. The project will also identify additional data elements beyond the existing USCDI core to address the unique needs of SCD research and quality improvement efforts.

Recommendation: ASH urges your Administration to continue to strengthen and build these data programs through additional federal support.

Advancing Biomedical Research

Medical research funded through the National Institutes of Health (NIH), the largest source of public funding for medical research in the world, has been a driving force behind many decades of advances that have improved the health of people in every state and community, providing cures and hope for patients and caregivers. Hematology research has also helped pave the way for many discoveries both within and outside of hematology. Discoveries made by hematologists have led to extraordinary advances in other fields of medicine, including new and better treatments for some of the world's deadliest and costliest diseases such as heart disease and stroke. Critical hematology research is supported by leading NIH institutes and centers, including the National Heart, Lung, and Blood Institute (NHLBI), National Cancer Institute (NCI), National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), and National Institute on Aging (NIA), among others. This work is essential to advancing our understanding and treatment of blood disorders and improving patient outcomes.

The practice of hematology has benefited from NIH investments which have led to the development of cutting-edge therapies in the field of hematology, including gene therapies for SCD, thalassemia, and hemophilia, and chimeric antigen receptor (CAR) T-cell therapies for certain blood cancers. These innovations are changing the practice of classical and malignant hematology, and the [ASH Agenda for Hematology Research](#) highlights key emerging and transformative areas of research that will launch the field into the next generation of therapies for hematologic conditions.³

Recommendation: ASH encourages you to continue to recognize the value of biomedical research and innovation by supporting robust funding for NIH and other federal agencies in your Fiscal Year 2026 budget. The Society welcomes the opportunity to work with your Administration to continue to support this pipeline for innovative therapies for patients.

Access to High-Quality Care for Patients

Drug Shortages

In 2023, this country experienced one of the worst chemotherapy drug shortages in its history, with fifteen indispensable chemotherapy drugs in short supply simultaneously. Sterile injectable drugs, including chemotherapies, are particularly vulnerable to shortages, which affects the care of patients with classical hematologic conditions and hematologic malignancies. Generally, these drugs are established low-cost treatments, and their shortages have significantly impacted ASH members' practices and patients. The incidence and duration of drug shortages is growing, and the shortages of critical hematology therapies can lead to delays in and rationing of care, negatively affecting treatment decisions, creating emotional distress for patients and families, and resulting in worse health outcomes. When drugs are in shortage, hematologists and other physicians are forced to make difficult treatment decisions, including administering alternative and notably more intense treatment regimens. These alternatives may result in significant toxicities, creating a host of challenges and complications for some patients. For others, alternative treatments can lead to relapse and even death.

The strain on patients and providers caused by drug shortages can be avoided. While the causes of these drug shortages are multiple and complex, there is an urgent need to mitigate current shortages and prevent future shortages.

Recommendation: ASH urges your Administration to explore changes to classify these drugs as essential medicines and policies that can be implemented by the Administration for Strategic Preparedness and Response. Additionally, we recommend working with Congress to improve transparency around shortages and support the manufacturing and purchasing of high-quality generic drugs produced through resilient supply chains. This includes manufacturing more sterile injectable drugs in the United States rather than overseas. As different remedies are considered, ASH would like to offer itself as a partner and a resource.

Additionally, ASH is concerned about the role of direct-to-consumer (DTC) advertising in potentially exacerbating shortages and affecting patient care. Pharmaceutical companies continue to advertise for drugs in shortage causing patients to ask their physicians about their prescription. The choice to pursue a certain therapeutic regime should be the result of consultation between a physician and patient. DTC advertising undermines these relationships and decisions about an individual's care.

Recommendation: ASH urges your Administration to examine the broader implications of direct-to-consumer advertising on the healthcare system and availability of medicines.

Maternal Health

ASH commends your first Administration for its focus on addressing the high rates of maternal mortality in the United States. There is a close connection between hematology and maternal health, given the risks of hematologic complications of pregnancy for all women. Hemorrhage and venous thromboembolism are two of the top five causes of death in pregnant women.⁴ Postpartum hemorrhage is a leading cause of morbidity and mortality in the United States,⁵ and women on anticoagulants or with anemia are at high risk of postpartum hemorrhage.⁶ Furthermore, women with inherited bleeding disorders have a risk of having a child with a bleeding disorder which impacts both their own care during delivery (mode of delivery) and may carry long-term implications for their child if affected.⁷ Additionally, women with anemia, women on blood thinners to control blood clots, women with blood cancer, and women with SCD are especially at high risk of pregnancy related complications including death.

Recommendation: ASH welcomes the opportunity to collaborate with your Administration to build on the progress made during your first term in reducing maternal mortality and improving maternal health outcomes, particularly for women affected by hematologic diseases and disorders.

Physician Payment Reform

ASH urges the Administration to work with Congress to reform physician payment, including reimbursement for cognitive care services. ASH firmly believes Medicare physician payment reform is essential to safeguard access to care for beneficiaries and support the sustainability of the healthcare and hematology workforce. Medicare physician payment has stagnated for the last two decades, declining by 29 percent when adjusted for inflation from 2001 – 2024. The Medicare Access and CHIP Reauthorization Act (MACRA) only provided statutory updates to the conversion factor from 2015 – 2019. Therefore, the lack of positive conversion factor updates and the MPFS' budget neutrality requirements have resulted in a series of statutorily required cuts to physician payment over the last four years, which Congress has repeatedly stepped in to mitigate. Despite Congress' interventions, Medicare reimbursement has not kept pace with the increasing cost of delivering care. Additionally, no other Medicare fee schedule has been subject to decreasing reimbursement, as they all include a mechanism for positive updates.

The continued erosion in Medicare physician reimbursement is distinctly acute for hematologists. Hematology, particularly classical hematology, is facing a severe workforce shortage, limiting access to much needed expertise in complex hematological disorders. The practice of hematology is rapidly evolving and becoming increasingly complex, requiring physicians to stay current with the latest innovations as they evaluate and recommend the most appropriate therapeutic options to their patients. As a result of this rapid innovation, the costs of practicing medicine, such as providing newly approved innovative cellular and gene therapies, are growing while Medicare reimbursement is shrinking. Additionally, early career physicians are expressing concerns of balancing the eroding Medicare reimbursement rates that cover physician and staff salaries and supplies while being burdened with significant medical school debt. Without adequate reimbursement, there are limited incentives for new physicians to pursue hematology.

For these reasons, we urge your Administration to work with Congress to:

- Include a baseline update to the Medicare Physician Fee Schedule conversion factor by providing an update of an unspecified percentage of the Medicare Economic Index (MEI) every five years. An annual inflation-based update will help Medicare reimbursement keep pace with evolving healthcare needs and ever-increasing healthcare costs while aligning MPFS policy with other Medicare fee schedules.
- Give the Secretary of HHS the authority to compare estimated utilization to actual utilization and adjust the conversion factor based on the difference (either over- or underutilization). Without positive updates to the MPFS conversion factor, the budget neutrality requirements exert greater downward pressure on Medicare reimbursement due to the redistributive impacts on MPFS payments. This pressure exacerbates the impression that specialties are pitted against one another when new codes are added to the MPFS, or a family of codes is recommended for an increase in valuation.
- Increase the outdated budget neutrality threshold of \$20 million to \$53 million and update it every five years equal to the cumulative increase in MEI.

Lastly, ASH believes that the current processes for valuing physician services should be evaluated. The complex care provided by hematologists is largely captured by evaluation and management (E/M), and other non-procedural, cognitive services. We appreciate that your Administration redefined and revalued E/M codes for the first time in decades, and encourage further consideration for comprehensive Medicare physician payment reform that would better reflect and capture the expertise, complex disease management, and development of treatment plans hematologists and other cognitive care specialists provide.

ASH participates in the American Medical Association's (AMA) RVS Update Committee (RUC) and believes it serves an important purpose in the valuation of specific services. However, we do not believe the process is as effective for E/M and non-procedural care as it is for procedures. Despite the best efforts of the AMA Current Procedural Terminology Editorial Panel, the RUC, and the Centers for Medicare & Medicaid Services (CMS), the payment challenges associated with E/M codes persist and are a driver of the shortage of hematologists and other cognitive specialists. As E/M and non-procedural services continue to be undervalued in the current payment system, the underlying challenges related to appropriately capturing complex cognitive care will persist and continue to place pressure on cognitive specialties.

Recommendation: ASH encourages your Administration to consider alternatives to more regularly and better support the definition and valuation of E/M and other non-procedural services. We welcome the opportunity to work with your Administration to improve reimbursement for hematological care and mitigate the persistent workforce shortages that result from inadequate reimbursement.

Access to Innovative Therapies

Advances in science have led to a recent surge of approvals for treatments for hematologic diseases and disorders. Many of these diseases are rare, requiring typically high-cost, highly specialized diagnostic, and therapeutic services. ASH members have been at the forefront of pioneering transformative therapies, yet the high costs of these innovations remain a significant barrier for care delivery. ASH developed a set of principles to ensure that all individuals have access to high-quality, clinically appropriate, and specialized care, including innovative therapies.⁸

Chimeric antigen receptor T-cell (CAR-T) therapy, first approved in 2017 for certain patients with lymphoma and leukemia, is a potentially life-saving cellular therapy for patients who have failed prior therapies. Several new CAR-T products and additional indications (e.g., multiple myeloma) are expected in the next few years. In addition, gene therapies for beta thalassemia and SCD have been developed, offering potential cures for diseases with previously limited treatment options. These innovative treatments come at a high cost, creating potential barriers to access.

Many of these innovative therapies are designed to be a one-time treatment, preventing the need for other, ineffective treatments, or a lifetime of maintenance therapies, but as noted, they come at a high cost. Innovative payment solutions, which have been slow to develop, are needed to address current barriers and prevent future barriers to access. As seen with CAR-T therapy, payment policies and solutions have not kept pace with the science and

approvals, and the lack of a sustainable payment solution has left a chilling effect on patient access to care for this potentially life-saving therapy.

ASH appreciated the thoughtfulness with which you approached reimbursement challenges associated with high-cost therapies in your first Administration. However, this remains a challenge for patients accessing these therapies.

Recommendation: ASH welcomes the opportunity to continue to work together to cover these therapies more effectively and ensure patient access. ASH encourages the Administration to ensure access to innovative therapies such as CAR-T.

Prior Authorization

Treatment decisions should be made between a physician and the patient; yet many times, policies, put in place by the Federal government or insurance companies, can impact these decisions. A 2022 physician survey by the AMA found that 86% of respondents reported that prior authorizations resulted in increased use of healthcare resources, leading to waste rather than the cost savings claimed by insurers.⁹ Approximately two-thirds of respondents reported that prior authorization requirements led to either diversion to ineffective initial treatments or additional office visits (64% and 62%, respectively).

Step therapy and prior authorization (PA), widely used amongst insurers to reduce costs, both have the potential to delay patient access to necessary, high-quality medication and to increase administrative burden for physicians. Unfortunately, these utilization management techniques are even used for commonly prescribed, evidence-based treatments, considered to be the standard of care, and many times limit the ability of the physician to prescribe the best/evidence-based standard of care for their patients. Many individuals with SCD, for which recurrent severe acute painful crises and chronic daily pain are the most common complications, are forced to switch from long-acting pain medications they have been taking for years because of failed PA attempts or a new PA must be filed every month for the same medication, placing an unnecessary administrative burden on the physician. Additionally, PA often delays care for both bone marrow transplants and cellular therapy, causing additional toxic therapy to be administered despite clear indications for these other treatments.

Not only are physicians and their staff affected by prior authorization, but patients also suffer undue burden and worse outcomes.

Recommendation: Recognizing that your first Administration focused on burden reduction in the Medicare program, ASH hopes your Administration will work with CMS to address the challenges associated with the prior authorization of medical services and prescription drugs.

Telehealth

The telehealth flexibilities implemented by CMS in response to the COVID-19 pandemic have transformed ASH members' practice, improving patient access to care, particularly for underserved and rural populations. Patients with hematologic conditions may not have access to hematologists in their communities, and telehealth can help them receive specialized care, including follow-up care and review of medication options and lab results, regardless of their geographic location.

ASH supports the permanent removal of originating site requirements and geographic restrictions for telehealth services. These barriers limit telehealth access and impede access to care. By permanently eliminating these restrictions, patients, regardless of where they live, can better access high-quality services via telehealth. This policy change would be particularly beneficial for patients in underserved or rural and remote areas who face challenges traveling to in-person appointments. Additionally, we support having CMS permanently remove the frequency limitations for telehealth services. Allowing physicians the capability to virtually care for patients when it is medically most appropriate and flexible for both the physician and the patient increases access to care. Our Society recognizes that CMS does not have the statutory authority to extend telehealth flexibilities permanently.

Recommendation: ASH encourages your Administration to work with Congress to grant CMS the authority to ensure that patients have access to these services on a permanent basis.

Thank you for the opportunity to share our health care priorities. ASH looks forward to working with your Administration to advance the health of all Americans including those who suffer from chronic illnesses. Should you have any questions, please contact Stephanie Kaplan, ASH Director of Government Relations and Public Health at skaplan@hematology.org or 202-776-0544.

Sincerely,

Belinda R. Avalos, MD

Belinda R. Avalos, MD
President

¹ <https://shabstracts.org/abstract/precision-medicine-an-individualized-approach-to-the-highest-utilizers-of-hospital-based-care/>

² National Academies of Sciences, Engineering, and Medicine. 2020. Addressing Sickle Cell Disease: A Strategic Plan and Blueprint for Action. Washington, DC: The National Academies Press. <https://doi.org/10.17226/25632>.

³ <https://www.hematology.org/research/ash-agenda-for-hematology-research>

⁴ Main, E. K., McCain, C. L., Morton, C. H., Holtby, S., & Lawton, E. S. (2015). Pregnancy-related mortality in California: causes, characteristics, and improvement opportunities. *Obstetrics and gynecology*, 125(4), 938–947. <https://doi.org/10.1097/AOG.0000000000000746>

⁵ Reale, S. C., Easter, S. R., Xu, X., Bateman, B. T., & Farber, M. K. (2020). Trends in Postpartum Hemorrhage in the United States From 2010 to 2014. *Anesthesia and analgesia*, 130(5), e119–e122. <https://doi.org/10.1213/ANE.0000000000004424>

⁶ Nyflot, L. T., Sandven, I., Stray-Pedersen, B., Pettersen, S., Al-Zirqi, I., Rosenberg, M., Jacobsen, A. F., & Vangen, S. (2017). Risk factors for severe postpartum hemorrhage: a case-control study. *BMC pregnancy and childbirth*, 17(1), 17. <https://doi.org/10.1186/s12884-016-1217-0>

⁷ James AH, Jamison MG. Bleeding events and other complications during pregnancy and childbirth in women with von Willebrand disease. *J Thromb Haemost*. 2007;5(6):1165-1169. doi:10.1111/j.1538-7836.2007.02563.x

⁸ <https://www.hematology.org/advocacy/policy-news-statements-testimony-and-correspondence/policy-statements/2019/access-to-hematology-care-in-an-age-of-innovation>

⁹ <https://www.ama-assn.org/system/files/prior-authorization-survey.pdf>