



January 24, 2017

2017

President

Kenneth Anderson, MD
Dana-Farber Cancer Institute
450 Brookline Avenue, Room M557
Boston, MA 02115-5450

phone 617-632-2144

fax 617-632-2140

kenneth_anderson@dfci.harvard.edu

President-Elect

Alexis Thompson, MD, MPH
Ann & Robert H. Lurie Children's Hospital of Chicago
225 E. Chicago Avenue
Box #30

Chicago, IL 60611

phone 312-227-4384

a-thompson@northwestern.edu

Vice President

Roy L. Silverstein, MD
Medical College of Wisconsin
Clinical Cancer Center
9200 W. Wosconsin Avenue
Milwaukee, WI 53226

phone 414-805-0815

rsilverstein@mcw.edu

Secretary

Robert A. Brodsky, MD
Johns Hopkins University
Ross Building, Room 1025
720 Rutland Avenue
Baltimore, MD 21205

phone 410-502-2546

brodso@jhmi.edu

Treasurer

Susan Shurin, MD
222 Quince Street
Unit 2C

San Diego, CA 92103

phone 240-328-8542

sxs15@yahoo.com

Councillors

Steven Allen, MD
John C. Byrd, MD
Mary Dinauer, MD, PhD
Cynthia E. Dunbar, MD
Terry Gernsheimer, MD
Michelle Le Beau, PhD
Martin Tallman, MD
Jane Winter, MD

Editors-in-Chief

Jason Gotlib, MD, *The Hematologist*
Bob Lowenberg, MD, PhD, *Blood*
Robert Negrin, MD, *Blood Advances*
Mikael Sekeres, MD, *ASH Clinical News*

Executive Director

Martha Liggett, Esq.
mliggett@hematology.org

The Honorable Tom Price, M.D.
Secretary Designee, Department of Health and Human Services
1211 Longworth House Office Building
Washington, DC 20515

Dear Dr. Price,

I am writing on behalf of the American Society of Hematology (ASH) to share the Society's priorities with you, and to offer the Society's expertise as a resource to the new Administration.

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 anemia, 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.

ASH is pleased to serve as a resource on hematologic issues, and we look forward to working with you to address the Society's priorities, outlined below.

Access to Care

ASH strongly supports access to affordable, high quality, health care for all Americans. ASH asks that any move to amend or repeal and replace the Patient Protection and Affordable Care Act (ACA) preserve access to hematologists and effective treatments for patients with hematologic diseases.

ASH was supportive of the private insurance reforms that now prohibit health plans from discriminating against patients with pre-existing conditions or imposing limits on lifetime benefits. Additionally, the Society is committed to ensuring that all individuals who need the services of a hematologist have access to one, and that all Americans have access to affordable and reliable coverage options. ASH remains deeply concerned about the need to reduce administrative burdens on physicians. The Society also supports the inclusion of basic consumer protections in all health plans to ensure that consumers understand coverage options.

ASH is also committed to making sure that all patients, especially those with hematologic conditions including both blood cancers and non-malignant diseases and disorders, have access to safe and effective care and treatment. On this front, ASH

continues to work to identify ways to combat high drug prices and limit out-of-pocket expenses for patients with hematologic conditions.

ASH is supportive at both the state and federal level of efforts to provide insurance parity for all approved evidence-based cancer treatments. Patient-administered chemotherapy has become more prevalent and is the standard of care, or frequently the only option for care, for many types of blood cancer. Parity would ensure that patient-administered chemotherapy is covered at the same rate under insurance as intravenous treatment. Additionally, ASH advocates against allowing private health insurance plans to require higher cost-sharing for medications in the specialty drug tiers than what is charged for drugs in a non-preferred brand drug tier. Many treatments for blood diseases and disorders are typically placed in specialty tiers, potentially requiring patients to pay in excess of \$10,000 each month for necessary medications. Moreover, these drugs are often used in combination, further making this cost is unmanageable, causing patients to choose to forego treatment.

Furthermore, as our nation continues to curb prescription drug abuse, we want to promote cautious, thoughtful, consideration in order to avoid unintended consequences for patients with chronic diseases. For example, it has been cited that some efforts to curb abuse have been backfiring for individuals with sickle cell disease. Despite the National Heart, Lung, and Blood Institute's evidence-based recommendations for treatment of sickle cell disease with opioid-based medications ([Evidence Based Management of Sickle Cell Disease: Expert Panel Report, 2014](#)), patients are often under treated, have delayed treatment, and face additional scrutiny when obtaining needed pain medication.

Research

The field of hematology has experienced a recent surge in progress thanks to novel technologies, new insights into the mechanisms of hematologic disorders, and cutting-edge targeted therapeutic strategies which have resulted in significant and meaningful advances in the effectiveness and quality of care. These foundational insights are reframing modern research, with the continued goal of improving outcomes and discovering cures for the most challenging hematologic diseases. Because this progress is largely due to federal investment in research, we ask that biomedical research support remain a top priority for the new Administration.

While certain blood disorders have benefited from the tremendous progress in clinical research and development of new therapies, other areas have continuing challenges. A wide variety of blood-related diseases – from malignancies such as lymphoma, leukemia, and multiple myeloma, to non-malignant diseases including sickle cell disease, blood platelet, and coagulation disorders – continue to be associated with significant morbidity and mortality, and demand attention to reduce their burden and improve the quality of care worldwide.

Today, the research community looks to emerging technologies and tools in the areas of genetics and epigenetics, gene therapies, and regenerative medicine to identify areas that have strong potential to make a dramatic impact on patient care across a range of diseases. Immune therapies of malignant hematologic disorders also shows great promise to improve patient outcome. The [ASH Agenda for Hematology Research](#) serves as a roadmap for the prioritization of research support across the hematology community, including recommendations for dedicated resources from funding agencies and foundations that will equip researchers today and in the future to make truly practice-

changing discoveries. These specific and critically important research questions must be answered to gain the insights that will launch the field into the next generation of care for hematologic conditions.

Sickle Cell Disease

ASH is dedicated to addressing the burden of sickle cell disease (SCD), and is undertaking a multifaceted initiative to improve outcomes for individuals with the disease both in the United States and globally. SCD is an inherited, lifelong chronic disorder affecting nearly 100,000 Americans, and is a growing global health problem that will touch nearly 30 percent more people globally in the next three decades. Over the past century, great advances have been made in the understanding and treatment of sickle cell disease (SCD). However, many basic scientific processes are still not fully understood, too few treatments have been developed, and most people who have SCD do not have access to the treatments that could improve the duration and quality of their lives. More attention must be paid to SCD at a federal level to ensure that patients have access to high-quality treatments, to assist in the development of more treatments, and to expand the physician workforce caring for this vulnerable population.

To work toward the goal of providing patients with SCD state-of-the-art care, ASH and other groups issued the [State of Sickle Cell Disease: 2016 Report](#), which evaluated the disease in four priority areas: access to care, training and professional education, research and clinical trials, and global health. ASH has also developed a [list of the top research and training priorities in SCD and sickle cell trait](#), which includes remaining unaddressed questions and specific research topics that could really move the field forward, with the hope of curing SCD in the future. ASH encourages the use of multi-disciplinary approaches to support these important areas, and urges stakeholder organizations to coordinate their funding in order to produce the greatest impact. Within the Department of Health and Human Services, a multi-agency approach would deliver advances faster, more economically, and more efficiently, to patients suffering from this debilitating disease in the United States and the world.

Physician Payment

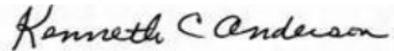
ASH will continue to advocate for appropriate physician reimbursement, adequate payment for cognitive physicians, and guaranteed reimbursement for preventive care.

ASH was supportive of the Medicare Access and CHIP Reauthorization Act (MACRA) in 2015, and believes that this legislation can help the health care system move towards a focus on quality. Since the passage of the legislation and the proposed and final rules issued in 2016 outlining the implementation of MACRA, ASH has been committed to working with its members to help them understand and comply with the new regulations for the Quality Payment Program. ASH submitted detailed comments for both the proposed rule and the final rule. In these comments, we shared our concern that there are an inadequate number of approved quality measures for many specialties, limiting physician participation in the program. There currently exists a disconnect between existing quality measures and what hematologists believe adequately measures care delivery for patients with hematologic malignancies and non-malignant blood disorders. This is especially problematic because many of the diseases in hematology are rare and low volume. Currently, there are only four quality measures for hematology, which are applicable to only some of the specialty. Efforts are therefore needed to strengthen MACRA in order to assure that it accomplishes its goal for

recognizing quality in the Medicare payment system. ASH is committed to continue to work with the Administration, the Centers for Medicare and Medicaid Services (CMS), and the health care community as a whole, to make improvements to the law and ensure smooth implementation of the Quality Payment Program.

ASH looks forward to working with you and the new Administration, along with the new Congress, to address the challenges and opportunities impacting hematology research and practice, as well as issues impacting hematology patients. Please feel free to contact either myself or Suzanne Leous, Director of Government Relations and Practice (sleous@hematology.org or 202-292-0258) if you have any questions or would like any additional information about hematology.

Sincerely,

A handwritten signature in black ink that reads "Kenneth C. Anderson". The signature is written in a cursive style with a clear, legible font.

Kenneth C. Anderson, MD
President