Dear Chairman Alexander and Ranking Member Murray:

I am writing on behalf of the American Society of Hematology (ASH) to share the Society’s policy priorities and to offer the Society’s expertise as a resource to you, especially as the Committee considers legislation to repeal or replace the Patient Protection and Affordable Care Act (ACA).

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 a strong advocate for access to affordable, high quality health care for all Americans and urges caution as the Committee considers changes to the ACA. 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 a strong advocate for access to affordable, high quality health care for all Americans and urges caution as the Committee considers changes to the ACA. The Society is very supportive of the private insurance reforms that now prohibit health plans from discriminating against patients with pre-existing conditions or imposing limits on annual and lifetime benefits. The public and private insurance reforms that are currently in place have been especially impactful for individuals with blood diseases and disorders. For example, the patient who has a blood cancer such as multiple myeloma and relies on a combination of expensive therapies, could reach their annual cap within a few months; meanwhile, the patient living with a blood disorder that has high treatment costs such as hemophilia, could reach their lifetime cap within a few years. Additionally, ASH wants to ensure that individuals eligible for Medicaid do not lose their ability to acquire affordable health care coverage and essential health benefits. This is critical for patients with sickle cell disease, an inherited chronic disorder affecting nearly 100,000 Americans who often experience lifelong complications including stroke, acute chest syndrome (a condition that lowers the level of oxygen in the blood), organ damage, and other disabilities.

The Society is committed to ensuring that all individuals who need the services of a hematologist have access to one, and that patients have affordable and reliable coverage options so that the most appropriate and effective treatment options are available to them. ASH supports comprehensive, evidence-based medicine, including access to preventive
options so that the most appropriate and effective treatment options are available to them. ASH supports comprehensive, evidence-based medicine, including access to preventive and long-term care practices, such as screening and patient education. Moreover, ASH advocates for greater coverage and support for cognitive care services. These services include comprehensive evaluation of patients, and the decision-making involved in complex diagnoses and determination of which treatment is most appropriate and effective. Cognitive care services are vital to many patients with hematologic diseases and disorders, which may involve few procedural treatments, but require complicated diagnostic strategies and other treatments, such as chemotherapy, immunotherapy, and lifelong medications.

ASH continues to work to identify ways to combat high drug prices and limit out-of-pocket expenses for patients with hematologic conditions and is supportive of allowing Medicare to negotiate drug prices with the pharmaceutical industry. ASH is also supportive at both the state and federal level of efforts to provide insurance parity for all approved evidence-based cancer treatments. 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. Specialty tier drugs that are included in most private health insurance plans typically require extremely high patient cost-sharing, with patients paying a percentage of the cost of these drugs, from 25% to 33% or more in coinsurance, rather than a fixed co-payment amount. Therapies for a number of blood diseases and disorders, including drugs like Gleevec – used to treat patients with leukemia – and treatments for hemophilia known as clotting factor therapies, are frequently placed in the specialty tier. The cost for many of these treatments can exceed $10,000 a month and if combined with other therapies, can result in extremely high and unmanageable out-of-pocket costs for many patients.

While certain blood disorders and diseases 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. These diseases demand attention to ensure timely and accurate diagnoses, increase access to and the availability of new and improved treatment, and reduce disease burden.

ASH will continue to advocate for the need to reduce administrative burden on physicians. Time spent fulfilling administrative duties negatively impacts time spent with the patient and is a significant contributor to physician burnout. Lastly, ASH supports an increase in federal support of health information technology (HIT), including easier and efficient access to health care records and history for patients. The Society will work to ensure federal support for interoperable HIT that is cost effective and reduces administrative expenses.

ASH looks forward to working with you to address the challenges and opportunities impacting hematology practice, as well as issues impacting hematology patients. Please feel free to contact either myself or Leslie Brady (lbrady@hematology.org, 202-292-0264) if you have any questions or would like any additional information about hematology.

Sincerely,

Kenneth C. Anderson, MD
President