



AMERICAN SOCIETY OF HEMATOLOGY

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2025

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The Honorable John Thune
Majority Leader
United States Senate
511 Dirksen Senate Office Building
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The Honorable Charles E. Schumer
Minority Leader
United States Senate
322 Hart Senate Office Building
Washington, D.C. 20510

Dear Majority Leader Thune and Minority Leader Schumer,

On behalf of the American Society of Hematology (ASH), I write to express our concern regarding the reconciliation package that passed the House on May 22 and urge the Senate to reject the changes to the Medicaid program adopted by the House. The impact of the *One Big Beautiful Bill Act* (H.R. 1) would be devastating for individuals with hematologic conditions that rely upon Medicaid for healthcare coverage by impeding access to the preventive and routine care necessary to manage their conditions.

ASH represents more than 18,000 clinicians and scientists committed to the study and treatment of blood and blood-related diseases, including malignant disorders such as leukemia, lymphoma, and myeloma, as well as classical (non-malignant) conditions such as sickle cell disease, thalassemia, bone marrow failure, venous thromboembolism, and hemophilia. For children and low-income adults with hematologic conditions, Medicaid provides much needed coverage and access to services to enable earlier diagnosis of chronic health conditions and access to affordable health care. This can prevent complications that are often accompanied by expensive emergency room visits. Below are examples of the impact Medicaid coverage has on patients with hematologic conditions.

- Approximately 100,000 Americans are living with sickle cell disease (SCD) an inherited, lifelong disorder, which results in patients' red blood cells becoming rigid and sickle shaped. The worst complications include stroke, acute chest syndrome, organ damage, other disabilities, and premature death. Half of those with the disorder are covered by Medicaid. Given the complexity of this disorder, Medicaid coverage is essential to ensuring individuals receive the full range of care and therapies needed to manage their condition.
- Lymphoma, a blood cancer, is the third leading cause of cancer among children and adolescents with later-stage diagnoses often linked to worse health outcomes. For these children, continuous Medicaid coverage before diagnosis was associated with a lower likelihood of late-stage lymphoma at diagnosis. However, only three in eight Medicaid-insured children and adolescents were continuously enrolled in the program prior to their diagnosis.¹
- Patients with malignant hematologic conditions, such as acute leukemia, need timely and comprehensive medical intervention to optimize survival rates.² Many of these younger and vulnerable patients will spend at least 12 months in the hospital following their diagnosis, which often leads to a need for support from Medicaid. Medicaid benefits, including transportation, are essential for individuals with acute leukemia, as they regularly need to travel for routine blood transfusions and chemotherapy during their course of treatment.

- There is a close connection between hematology and maternal health, with hemorrhage and venous thromboembolism two of the top five causes of death in pregnancy. Currently, Medicaid covers around 40% of births nationally and is a vital part in combatting rising maternal and infant mortality rates.³

Cuts to the Medicaid program, as included in the *One Big Beautiful Bill Act*, will have a disastrous impact on some of the most vulnerable individuals in the country. These individuals will lose access to the preventive care that keeps them healthy and treatments needed to manage chronic and acute conditions, forcing them to seek care in more costly settings. According to the Congressional Budget Office, the House-passed bill would lead to 10.3 million people losing some coverage, and 7.8 million people becoming uninsured. The inclusion of work reporting requirements and more frequent eligibility verification in the legislation will create barriers to access. Data shows that most adults on Medicaid are either already working or are unable to work.⁴ Work reporting requirements result in loss of coverage for many who should qualify due to red tape. This will place a greater financial burden on states, resulting in reduced eligibility and services for low-income populations.

ASH appreciates that the House provided certain exceptions to the Medicaid work reporting requirements. However, we do not believe that these provide strong enough guardrails to protect coverage for the most vulnerable, including those with hematologic diseases. Specifically, the legislation provides an exception for certain individuals who are medically frail or otherwise have special medical needs, which will be defined by the Secretary. This exception includes those with serious and complex medical conditions, which ASH believes will include SCD and cancer. However, the lack of clarity about these definitions, how they will be verified, and the frequency of verification is cause for concern. For individuals undergoing cancer treatment or experiencing SCD-related pain crises, demonstrating and verifying their condition to states may be extremely burdensome. ASH is concerned that operationalizing these exceptions may ultimately result in inappropriate coverage losses.

As Senate leaders, we urge you to protect health care access for our patients and your constituents by rejecting the changes to the Medicaid program included in the House-passed budget resolution, and encouraging your colleagues to oppose these detrimental provisions. Medicaid is crucial for providing care to the most vulnerable individuals who are impacted by hematologic conditions, and it is imperative that Congress work to protect this vital program.

Sincerely,



Belinda Avalos, MD
ASH President

CC: *United States Senate*

¹ <https://ashpublications.org/bloodadvances/article/9/2/280/525948/Medicaid-coverage-continuity-is-associated-with>

² <https://ashpublications.org/blood/article/144/Supplement%201/2343/532132/Medicaid-Expansion-and-Cancer-Specific-Survival>

³ <https://www.kff.org/policy-watch/top-5-things-to-know-about-women-and-medicare-ahead-of-the-election/>

⁴ <https://www.kff.org/policy-watch/implementing-work-requirements-on-a-national-scale-what-we-know-from-state-waiver-experience/#:~:text=KFF%20analysis%20shows%20that%2092,number%20of%20Medicaid%20enrollees%20working>.