



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

November 24, 2025

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
289 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, MS
Wendy Stock, MD

Executive Director

Martha Liggett, Esq.

The Honorable Mehmet Oz, M.D.
Centers for Medicare and Medicaid Services
7500 Security Blvd.
Baltimore, MD 21244

Dear Administrator Oz,

On behalf of the American Society of Hematology (ASH), we write to respectfully request that you consider the needs of individuals living with complex hematologic conditions as you implement the community engagement requirements of the *One Big Beautiful Bill Act* (OBBBA) (P.L. 119-21). It is imperative that those in the Medicaid expansion population with serious and complex conditions, like sickle cell disease (SCD) and blood cancers, can continue to receive the care needed 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 SCD, thalassemia, bone marrow failure, venous thromboembolism, and hemophilia. For children and low-income adults with hematologic conditions, Medicaid provides critically needed coverage and access to services to enable earlier diagnosis of conditions and access to affordable health care.

Section 71119 of the law requires states to impose community engagement requirements for adults in the Medicaid expansion population aged 19–64 (under age 65, $\leq 138\%$ FPL). Enrollees in this population will be required to complete 80 hours of qualifying activities per month (i.e., work, community service, work program, half-time education, or income equivalent) to maintain their Medicaid eligibility. Importantly, Congress considered the health care coverage needs of those living with serious medical conditions and provided for mandatory exceptions from these community engagement requirements to be further defined via regulation.

ASH urges the Administration to ensure that the exceptions are defined in a manner that protects those with serious and complex hematologic conditions who rely upon Medicaid coverage. Additionally, we urge the Administration to ensure that the requirements to qualify for these exceptions are not unnecessarily burdensome.

Individuals living with complex hematologic conditions require regular access to highly specialized care to appropriately manage their conditions. Approximately 100,000 Americans are living with SCD, an inherited, lifelong disorder, which results in patients' red blood cells becoming rigid and sickle shaped.ⁱ The worst complications include stroke, acute chest syndrome, organ damage, disabilities, and premature death. People with SCD often experience a pain crisis or vaso-occlusive (VOC) episode which causes sudden and severe pain, most commonly in the hands, feet, chest, and back.ⁱⁱ VOCs are the primary reason for emergency room visits and hospitalizations for people with SCD. Up to 67% of Americans with SCD experience at least three VOC pain crises per year, with the average hospital admission for a severe pain crisis being five days.ⁱⁱⁱ

These hospitalization and frequent visits to the emergency room can interfere with a person's ability to maintain employment. One cohort study found that SCD patients with severe pain crises are more likely to be unemployed.^{iv} About half of people with SCD are enrolled in Medicaid, making the implementation of the exceptions to the community engagement requirements of particular concern for these individuals. Without consistent coverage and regular care, SCD patients may rely on emergency services leading to an inefficient use of valuable healthcare resources, which then adds costs to the healthcare system. For example, without continuous coverage, SCD patients become reliant on emergency services, contributing to \$2.4 billion in avoidable annual ED costs according to government data.^v

For blood cancers, such as lymphoma and acute leukemia, the intensity of treatment and length of recovery make it difficult to maintain employment or regular daily activities. Lymphoma, a blood cancer, is the third leading cause of cancer among adolescent/young adults (15-39 years). Despite advances in treatment options, later-stage diagnoses are often linked to worse health outcomes. For these patients, continuous Medicaid coverage before diagnosis is associated with a lower likelihood of late-stage lymphoma. However, only three in eight Medicaid-insured children and adolescents are continuously enrolled in the program prior to their diagnosis.^{vi} Acute leukemia is a rapidly progressive disorder that requires timely and comprehensive medical intervention to optimize survival rates.^{vii} Many young patients spend more than 12 months in the hospital following diagnosis, making it unrealistic for them or their caregivers to sustain employment during treatment. Medicaid benefits, including coverage for transportation to frequent transfusions and chemotherapy services, provide a vital safety net for these patients who cannot work and whose families often face lost income alongside the financial burden of care.

Request:

The Society recommends that Medicaid beneficiaries with SCD and blood cancers be excluded from the OBBA's community engagement requirements.

Individuals living with complex hematologic conditions, including SCD and blood cancers face significant barriers to maintaining consistent employment due to the intensity and unpredictability of their medical condition. Frequent hospitalizations, severe pain crises, long treatment regimens, and extended recovery times often make work infeasible for both patients and their caregivers. As a result, conditioning Medicaid eligibility on community engagement requirements will create undue hardship and risk the loss of coverage for individuals whose conditions clearly prevent them from working.

The legislation allows the Secretary to define "medically frail," "special medical needs," "physical disability," and/or "complex medical condition" to exclude certain Medicaid beneficiaries from the community engagement requirements (P.L. 119-21, Sec. 71119(a); (xx)(9)(A)(ii)(V)). The Centers for Medicare & Medicaid Services has previously defined medically frail to include people with serious and complex medical conditions in the Medicaid population at 42 CFR §440.315(f), which allows states to provide alternative benefits specifically tailored to meet the needs of certain Medicaid population groups. In this case, CMS has already defined the term medically frail to treat certain beneficiaries differently in the Medicaid program.

SCD, and blood cancers are serious and complex medical conditions based on symptoms and treatments required to manage these diseases successfully. The definition that CMS uses to define special needs individuals in the Medicare Advantage program at 42 U.S.C. §422.2 bolsters this position.^{viii} This section defines severe or disabling chronic conditions to include cancer, excluding pre-cancer conditions or in-situ status, and severe hematologic conditions including SCD (excluding sickle cell trait). Furthermore, CMS considers chronic conditions as those expected to last at least 12 months or until the individual's death in its definition of Medicare chronic care management services. Based on these two precedents, ASH believes that previous agency policy clearly supports the exclusion of individuals living with SCD and certain hematologic malignancies from the Medicaid community engagement requirements.

The Society recommends that CMS ensure redetermination policies do not create delays or barriers to timely access to care for those in excluded populations.

Under Sec. 71107 of the OBBA, States will be required to verify exemptions in (at least) the month before application and (at least) one month between eligibility. States will be required to look back one or more consecutive months to

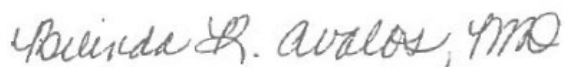
confirm compliance with the requirements. Under the statute, eligibility will be redetermined every six months to verify compliance. Given the complexity of treatment for certain hematologic conditions, most affected individuals will not be able to meet the community engagement requirements and may be excluded. Burdensome reporting or verification requirements could result in inappropriate disenrollment or denial of coverage for those who urgently need continuous care. Patients and caregivers manage numerous responsibilities related to their therapeutic regimens, and a complicated process will be unnecessarily burdensome.

To reduce patient burden, CMS should ensure that patients who qualify for the medically frail exclusion do not have to verify this exclusion more often than the required Medicaid eligibility verification period of once every six months. As the new requirements are implemented, we ask that states be directed to delay procedural terminations during the rollout period to prevent the disenrollment of patients who may experience barriers in completing required documentation. When making ex parte verifications, ASH encourages CMS and states to use available information, including applicable diagnosis codes to determine which individuals qualify for an exclusion from the community engagement requirements. This will help the state determine eligibility without placing the burden on the excluded individual. ASH is available to serve as a resource to CMS and states regarding relevant diagnosis codes for the hematologic conditions that need protection.

The Society is grateful the OBBBA stresses that notice of new Medicaid requirements and exemptions must be sent via mail (or through electronic format, if elected by the individual) and through at least one other modality such as telephone, e-mail, text messages, or website postings. We ask that CMS ensure applications are designed to be simple, use plain language, and be mobile-friendly.

We hope to serve as a resource to CMS throughout this process, ensuring that patients with hematologic conditions are appropriately considered and afforded the flexibility permitted by law under the Medicaid community engagement requirements. The Society welcomes the opportunity to meet with you and your team to discuss this further and will be following up on this communication. In the interim, please contact ASH Chief Policy Officer, Suzanne Leous (sleous@hematology.org) and Manager, Policy & Practice, Myra Masood (mmasood@hematology.org) if you require further information or have any questions.

Sincerely,



Belinda Avalos, MD
ASH President

ⁱ <https://www.cdc.gov/sickle-cell/complications/pain.html>

ⁱⁱ <https://pmc.ncbi.nlm.nih.gov/articles/PMC10329958/>

ⁱⁱⁱ <https://pmc.ncbi.nlm.nih.gov/articles/PMC10329958/>

^{iv} <https://ashpublications.org/blood/article/132/Supplement%201/4930/262374/Association-between-Employment-Status-and>

^v <https://www.cms.gov/About-CMS/Agency-Information/OMH/Downloads/Opioid-Prescription-in-Medicare-Beneficiaries-Report.pdf>

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

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

^{viii} <https://www.cms.gov/medicare/enrollment-renewal/special-needs-plans/chronic-conditions>