American Society of Hematology
Helping hematologists conquer blood diseases worldwide

July 23, 2026

The Honorable Mike Johnson
Speaker of the House
Washington, DC 20515

The Honorable John Thune
Majority Leader, U.S. Senate
Washington, DC 20510

The Honorable Hakeem Jeffries
Minority Leader
U.S. House of Representatives
Washington, DC 20515

The Honorable Charles Schumer
Minority Leader U.S. Senate
Washington DC, 20510

Dear Speaker Johnson, Majority Leader Thune, Minority Leader Jeffries, and Minority Leader Schumer,

On behalf of the American Society for Hematology (ASH), we write to urge Congress to conduct oversight of the Centers for Medicare & Medicaid Services' (CMS) implementation of the community engagement requirements of the One Big Beautiful Bill Act (OBBBA), and to encourage the agency to revise its interim final rule to ensure it accurately reflects Congressional intent and statute as enacted. Specifically, ASH is concerned that the interim final rule (IFR) improperly narrows the statutory exemption for medically frail individuals by requiring both the presence of a serious or complex medical condition and a determination that this condition limits the individual's ability to meet the community engagement requirement.

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 critical coverage and access to services that enable earlier diagnosis and affordable ongoing access to vital healthcare services.

Section 71119 of the OBBBA requires states to implement community engagement requirements for adults in the Medicaid expansion population. Congress explicitly recognized, however, that some beneficiaries should be exempt from community engagement requirements because of their medical circumstances and directed the Secretary of the Department of Health and Human Services to exempt beneficiaries who are medically frail. The statute included those beneficiaries with a serious or complex medical condition as medically frail. This and the other stated exemptions are intended to protect

individuals whose conditions place them at risk of losing coverage because they are unable to satisfy the community engagement requirements.

Definition of Medical Frailty

As directed in the legislation (Sec. 71119(a); (xx)(9)(A)(ii)(V)), the Secretary is responsible for defining the terms "medically frail," "special medical needs," "physical disability," and/or "complex medical condition" for purposes of implementing the statutory exemptions from the community engagement requirement. While Congress delegated authority to define these terms, it did not authorize CMS to narrow the categories of individuals eligible for an exemption by imposing additional substantive eligibility criteria. Congress provided for these exemptions to allow medically vulnerable individuals to continue to access Medicaid coverage, thereby addressing their serious medical conditions rather than seeing their conditions worsen because they are unable to meet these requirements.

The interim final rule (codified at 42 C.F.R. § 435.554; 91 Fed. Reg. 33348 (June 3, 2026)) (IFR) appropriately identifies the statutory categories of individuals who may qualify as medically frail. However, it exceeds the authority granted by Congress to CMS by requiring an individual who is medically frail, based on having a serious or complex medical condition, to demonstrate that the condition *significantly impairs the individual's ability to comply with the community engagement requirement.* As a result, individuals with serious hematologic conditions who fall within the statutory categories may be denied an exemption unless they can satisfy an additional standard that Congress did not intend.

In the proposed rule, CMS suggests that an individual capable of working cannot be considered medically frail. That rationale overlooks a central reality for hematology patients: many can work only because their underlying condition is actively managed through the care they receive through Medicaid—hydroxyurea and transfusions for sickle cell disease, or clotting factor for hemophilia, for example. Removing that coverage would not confirm an ability to work; it would destabilize the very condition on which the determination rests.

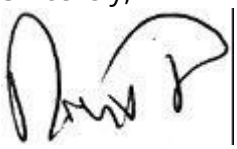
The statute further directs states to use available data sources, including diagnosis codes and claims data, to automatically identify people who qualify as medically frail. However, the IFR states that diagnosis and claims data alone are insufficient because that data does not establish the degree to which an individual's condition impairs compliance with the community engagement requirement. At the same time, the IFR does not provide objective standards for assessing the severity of a condition or determining what constitutes sufficient impairment to qualify for an exemption.

Absent clear and objective criteria, states will be left to develop their own approaches to defining functional impairment, resulting in inconsistent application of the statute across state Medicaid programs while creating uncertainty for beneficiaries. As a result, states, beneficiaries, and healthcare providers will likely be required to generate and submit additional documentation to establish eligibility for an exemption, creating significant administrative burden for all involved. Healthcare providers already face significant workforce and resource constraints. Requiring them to take on responsibilities beyond documenting a patient's medical condition for eligibility determinations would impose an additional administrative burden, diverting valuable time and attention away from providing direct patient care.

Congress established these exemptions to protect medically vulnerable individuals from losing Medicaid coverage, not to create additional evidentiary hurdles that limit access to those protections. Therefore, we respectfully urge Congress to use its oversight authority to ensure that CMS revises the IFR to be consistent with the statutory language and intent. Prompt attention is especially important, given that the IFR takes effect on July 31, 2026.

Should you have any questions or wish to discuss these issues further, please contact ASH Manager, Policy & Practice, Myra Masood (mmasood@hematology.org).

Sincerely,



Robert Negrin, MD

President

Cc: Senate Committee on Finance, House Committee on Energy and Commerce