American Society of Hematology
Helping hematologists conquer blood diseases worldwide

2026
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September 1, 2026

Erica Schwartz, MD, MPH, JD
Director
Centers for Disease Control and Prevention
1600 Clifton Road
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Dear Dr. Schwartz,

The American Society of Hematology (ASH) congratulates you on your confirmation as the Director for the Centers for Disease Control and Prevention (CDC). As you assess the Agency's current structure, evaluate recent changes, and set priorities for your tenure, ASH welcomes the opportunity to share recommendations for strengthening CDC programs and policies that support Americans living with blood disorders. ASH has long valued its partnership with CDC, and we stand ready to serve as a resource to you and your team as you advance initiatives that affect hematologists and the patients they serve. We look forward to building on this longstanding relationship under your leadership.

ASH represents more than 18,000 clinicians and scientists committed to studying and treating blood and blood-related diseases, many of which cause chronic symptoms. These disorders encompass malignant hematologic disorders such as leukemia, lymphoma, and multiple myeloma, as well as classical (or non-malignant) conditions such as sickle cell disease (SCD), thalassemia, bone marrow failure, venous thromboembolism (VTE), and hemophilia. ASH continues to develop many programs and resources to support the Society's members, including evidence-based clinical practice guidelines to help improve the quality of hematologic care provided to patients.

We are also writing with an immediate request that you reinstate the CDC's Division of Blood Disorders and Public Health Genomics (DBDPHG) within the National Center on Birth Defects and Developmental Disabilities, the group responsible for implementing programs critical to people with blood disorders.

DBDPHG plays a vital role in working directly with states, patients, families, healthcare providers, and treatment centers to reduce the impact of serious blood disorders such as SCD, thrombosis, thrombophilia, hemophilia, thalassemia, and more. For more than a year, DBDPHG has been lacking the staff necessary to fulfill its statutory mandate and administer the funds for its work as appropriated by Congress.

As noted in this letter to Secretary Kennedy dated April 8, 2025, ASH along with nearly 100 other groups that represent millions of Americans living with chronic and acute blood-related disorders, is deeply concerned by the HHS' decision to place the DBDPHG staff on administrative leave. Without experienced staff in place, the Division cannot carry out its core public health mission, leaving critical programs without oversight, coordination, or accountability. As federal coordination has stalled, states and grantees are being forced to absorb responsibilities they were never funded or equipped to do, diverting limited resources away from patient care and program implementation.

One example of a thriving DBDPHG program that has been disrupted is the Sickle Cell Data Collection Program, which has been critical in collecting and analyzing longitudinal data about people living with SCD in the U.S. Through the program, which was implemented during President Trump's first term, the CDC awards SCD data collection grants to states, academic institutions, and non-profit organizations to gather information on the prevalence of SCD and related health outcomes, complications, and treatment that people with SCD receive. Under the current appropriation of $6 million, sixteen states, which represent approximately 50% of the Americans living with SCD, participate in the data collection program, with data being collected from multiple sources to create individual health care utilization profiles. The Division's current state of uncertainty has led to a number of immediate challenges—for example, grantees facing difficulties in planning with the risk of losing key staff with essential program and data expertise; pauses in data collection and analysis; and disruptions to patient care by affecting the flow of aggregate data from the grantees to clinics about their patient lists (including information clinics are unable to get elsewhere such as actual prescription fills, and, emergency department utilization). These changes are already weakening national coordination for SCD surveillance, slowing analyses, delaying reporting, and increasing administrative burden for state teams. Without restored federal coordination, states risk moving toward fragmented methods and inconsistent reporting expectations, undermining the comparability and timeliness of national data.

We are already seeing reduced visibility and utility of SCD surveillance findings, along with early signs that the national data infrastructure built through years of federal investment is beginning to erode. Continued support and leadership for this program is essential to help sustain, strengthen, and expand the program's current efforts, which will help enable individuals living with this disease to receive adequate care and treatment. One example from Michigan illustrates a broader problem affecting all participating states: states continue to submit annual surveillance data to CDC, but without central CDC leadership, state-specific data on the CDC website and in the Agency's systems can no longer be updated. As a result, public data are becoming outdated across the program, and key analyses, including an updated prevalence estimate in the United States, and a Transformed Medicaid Statistical Information System (T-MSIS) Analytic Files (TAF)-Medicaid comparison, remain delayed. While core surveillance continues at the state level in a limited way, the program's value for informing policy, research, and care is significantly reduced.

Additionally, ASH is concerned that the Centers for Medicare & Medicaid Services' interim final rule implementing Medicaid community engagement requirements under H.R. 1 may improperly narrow the medically frail exemption by requiring both a serious or complex condition and proof that the condition limits compliance. Because CMS leaves states significant discretion to define qualifying conditions and verification processes, timely SCDC data could help Medicaid agencies assess the impact on people with SCD and shape policies that reflect their real-world needs. Without central coordination to translate and disseminate these findings, states may miss a critical opportunity to use actionable surveillance data when implementation decisions are being made.

Other programs that focus on blood disorders including hemophilia, thalassemia, and VTE, for example, are detailed in this letter. The impact of this Division's role on patient care, research, and public health cannot be overstated. **We respectfully urge you to take immediate action in coordination with HHS to reinstate the team charged with implementing these vital and impactful programs.**

One other significant issue that ASH is deeply concerned about is the state of the Advisory Committee on Immunization Practices (ACIP) and various vaccine policies, including the Executive Order issued on August 10 on *Delivering Gold Standard Childhood Vaccine Recommendations for Americans*. Vaccines are critical for individuals with hematologic conditions, many of whom are immunocompromised due to their disease, treatment, or both, and face heightened risk of severe, potentially life-threatening infections. Timely, evidence-based vaccine recommendations are especially important for patients with leukemia, lymphoma, SCD, bone marrow failure syndromes, hemophilia, and other inherited or acquired bleeding disorders. Maintaining access to recommended vaccines and strong community vaccination rates are essential to protect these patients and their families, especially when some individuals cannot safely receive certain vaccines or may have a reduced immune response. As vaccine schedules continue to be considered, steps should be taken by CDC to restore a strong ACIP that values the long-established public process for ACIP nominations and member selection, ensuring that experience and subject-matter expertise are prioritized. Maintaining access to and trust in life-saving immunizations requires a continued commitment to transparent, independent review of evidence-based recommendations by unbiased clinical experts.

As the new CDC Director, ASH looks forward to working with you on vaccine-related issues affecting patients with hematologic conditions and appreciates your commitment to evidence-based decision-making informed by appropriate expertise and stakeholder feedback.

ASH welcomes the opportunity to work with you to advance CDC's mission and improve the public health of individuals with hematologic conditions. Should you have any questions, please contact Stephanie Kaplan, ASH Director of Government Relations and Public Health, at skaplan@hematology.org or 202-776-0544.

Sincerely,

Robert Negrin, MD
President