September 4, 2026

Erica Schwartz, MD, MPH, JD
Director
Centers for Disease Control and Prevention
1600 Clifton Road
Atlanta, GA 30329

Dear Dr. Schwartz,

The undersigned organizations, representing individuals living with blood disorders, health care providers, researchers, and public health professionals, congratulate you on your confirmation as Director of the Centers for Disease Control and Prevention (CDC). As you begin your tenure and assess the agency's priorities, we welcome the opportunity to support your efforts to strengthen CDC programs that support Americans living with blood disorders. We look forward to working with you and your team to advance the CDC's public health mission and improve outcomes for patients and communities across the country.

For more than 50 years, the CDC's Division of Blood Disorders & Public Health Genomics (DBDPHG), housed within the National Center on Birth Defects and Developmental Disabilities (NCBDDD), has played a unique and critical role in supporting people living with blood disorders. The Division works with states, health care providers, treatment centers, researchers, patients, and families to advance surveillance, data collection, laboratory services, technical assistance, and public health programs addressing conditions including sickle cell disease (SCD), hemophilia, thalassemia, blood clots, and other inherited and acquired blood disorders.

DBDPHG's work has produced meaningful public health and patient benefits. For example, the Sickle Cell Data Collection (SCDC) Program has helped states and other grantees collect and analyze longitudinal data on health care utilization, complications, treatment, and outcomes among people living with SCD. These data help providers and public health officials identify gaps in care, improve coordination, and better understand the needs of individuals living with SCD. Similarly, CDC-supported hemophilia programs and research have contributed to improvements in the early identification and management of inhibitors, which can cause serious and potentially life-threatening complications for people with hemophilia. Additionally, people at highest risk for blood clots are using CDC supported or developed tools to recognize symptoms and seek timely care, improving outcomes for nearly 900,000 people each year.

These successes demonstrate why sustained federal leadership and expertise are essential. DBDPHG's programs depend on experienced staff who possess the technical knowledge, institutional expertise, and relationships necessary to administer grants, maintain surveillance systems, analyze data, provide technical assistance, and coordinate with states, providers, and communities. Funding alone cannot ensure that these programs function effectively without the personnel necessary to carry out this work.

Unfortunately, DBDPHG has not been operating at full capacity for more than a year following significant staffing disruptions. With 29 of the Division's 32 staff placed on administrative leave, the resulting loss of institutional knowledge, technical expertise, and leadership has affected the states, grantees, providers, and patients that rely on the Division.

The consequences are already being felt across the blood disorders community. The SCDC Program has experienced disruptions affecting the flow of aggregated data to clinics, including information that may not be available through other sources, such as prescription fills and emergency department utilization. In hemophilia, Community Counts supports surveillance across more than 140 Hemophilia Treatment Centers and provides free inhibitor testing to eligible patients. Inhibitors prevent clotting factor treatments from working effectively and are among the most serious complications of hemophilia. People with hemophilia who develop an inhibitor are twice as likely to be hospitalized for a bleeding complication and are at increased risk of death, underscoring the importance of maintaining access to regular inhibitor testing. For individuals living with thalassemia, DBDPHG provides clinical education and strategic planning that help providers deliver appropriate care to patients who require lifelong transfusions. The Division's monitoring of blood and blood products and transfusion-related complications also helps promote safer transfusions and prevent infections. More broadly, disruptions to federal coordination, surveillance, data collection, grant administration, and technical assistance risk creating gaps in care and public health infrastructure that cannot be quickly or easily restored.

These challenges are particularly concerning because the Division and its programs continue to receive congressional support. Congress has appropriated funding for these activities because they provide unique public health functions that are not readily replicated elsewhere. The issue is therefore not simply whether these programs are funded, but whether the Division has the staffing, leadership, and expertise necessary to ensure that those federal investments are used as Congress intended.

As you assess the CDC's structure and priorities, we respectfully ask you to:

- **Restore DBDPHG to full operational capacity** by ensuring that the Division has sufficient qualified staff, leadership, and technical expertise to fulfill its statutory mission.
- **Ensure continuity of DBDPHG's core programs and functions**, including surveillance, data collection, laboratory services, grant administration, technical assistance, and coordination with states, providers, researchers, and patient communities.
- **Assess and address the disruptions that have occurred over the past year**, including gaps in surveillance, data collection, grant implementation, laboratory services, and technical assistance, and take steps to restore continuity where necessary.
- **Engage directly with patients, providers, grantees, states, and other stakeholders** to understand the impact of these disruptions and ensure that the Division's programs continue to address the needs of the communities they serve.

The blood disorders community stands ready to work with you and the CDC to ensure that DBDPHG can continue its longstanding work to prevent complications, improve health outcomes, strengthen public health surveillance, and support the patients and families who depend on these programs.

We urge you to restore DBDPHG's staffing, leadership, and operational capacity as an early priority of your tenure. Congress has recognized the importance of these programs through continued authorization and funding.

Thank you for your leadership and consideration. We look forward to working with you and your team to strengthen the CDC's efforts on behalf of people living with blood disorders.

Sincerely,

American Society for Clinical Pathology
American Society of Hematology
American Society of Pediatric Hematology/Oncology
American Thrombosis and Hemostasis Network
Arizona Bleeding Disorders
Bleeding Disorders Alliance Illinois
Bleeding Disorders Association of South Carolina
Bleeding Disorders Council of California
Bleeding Disorders Foundation of North Carolina
Bleeding Disorders of the Heartland
Bridges Pointe, Inc.
Cayenne Wellness Center and Childre's Foundation
CHES Foundation
Coalition for Hemophilia B
Cooley's Anemia Foundation
Foundation for Women & Girls with Blood Disorders
Gateway Bleeding Disorders Association
Genetix Biotherapeutics Inc.
Hemophilia Alliance
Hemophilia Association of New York, Inc.
Hemophilia Association of the Capital Area
Hemophilia Federation of America
Hemophilia Foundation of Maryland
Hemophilia Foundation of Southern California
Hemophilia of Georgia
Martin Center Sickle Cell Initiative
MTS Sickle Cell Foundation, Inc.
National Bleeding Disorders Foundation
National Blood Clot Alliance
New England Hemophilia Association
New York City Hemophilia Chapter
Piedmont Health Services and Sickle Cell Agency (NC)
Sick Cells
Sickle Cell Anemia Resource Foundation

Sickle Cell Consortium
Sickle Cell Disease Association of America, Inc.
Sickle Cell Disease Association of Illinois
Sickle Cell Disease Partnership
Sickle Cell Foundation of Georgia, Inc.
Sickle Cell Foundation of Greater Montgomery, Inc.
Sickle Cell Foundation of MN
Sickle Cell Foundation, Inc
Sickle Cell Medical Advocacy Inc.
Sickle Cell Prodigy
Sickle Cell Warriors of Wisconsin
Southeast Alabama Sickle Cell Association Inc.
Tennessee Hemophilia & Bleeding Disorder Foundation
The Sickle Cell Association of New Jersey
The Sickle Cell Council of New Mexico, Inc.
Uriel E. Owens Sickle Cell Disease Association of The Midwest
Virginia Bleeding Disorders Foundation (formerly Virginia Hemophilia Foundation)
VWD Alliance
Western Pennsylvania Bleeding Disorders Foundation