

April 8, 2025

Robert F. Kennedy, Jr.
Secretary, U.S. Department of Health and Human Services
Hubert H. Humphrey Building
200 Independence Avenue, SW
Washington, DC 20201

Sent via email to Darcie.johnston@hhs.gov

Dear Secretary Kennedy,

The undersigned organizations represent millions of Americans living with chronic and acute blood-related disorders that can cause lifetime disability, premature death and significantly impact the cost of healthcare in this country. Blood disorders in the United States (U.S.) are a major public health problem, demanding a strong and coordinated federal response.

We are deeply alarmed by the Department of Health and Humans Services' (HHS) recent decision to place the staff of the Centers for Disease Control and Prevention's (CDC) Division of Blood Disorders and Public Health Genomics (DBDPHG) on administrative leave, effectively dismantling this critical Division. This abrupt action with no communication regarding plans for the future of its essential programs runs counter to your publicly stated commitment to addressing chronic disease in the U.S. We urge you to immediately reinstate this Division.

The 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 thrombosis, thrombophilia, hemophilia, sickle cell disease (SCD) and thalassemia, and more. Many of these conditions are genetic in nature and are influenced by inherited factors and cannot simply be mitigated by lifestyle changes. While each blood disorder affects a particular segment of the U.S. population, and has unique characteristics, there are many common threads that magnify their overall impact on affected individuals and the healthcare system at large. DBDPHG's programs have been built over time under the leadership of staff with significant expertise, and with the investment and partnership of states, impacted communities and healthcare providers. Eliminating the DBDPHG would have severe and irreversible consequences, including:

- Disrupting life-saving public health programs and cutting off essential patient resources
- Halting critical research and data collection that guide treatment and prevention efforts
- Weakening partnerships with states, healthcare providers, and affected communities
- Increasing preventable hospitalizations, complications, and fatalities

The following summarizes a few of the many examples of the impact that the Division's work and programs continue to have on our community and all U.S. citizens.

- SCD affects approximately 100,000 Americans and is an inherited, lifelong disorder, which results in patients' red blood cells becoming rigid and sickle shaped. Sickle cells can get stuck in blood vessels and block blood flow, causing pain and organ infarctions. The worst complications include stroke, acute chest syndrome (a condition that lowers the level of oxygen in the blood), organ damage, other disabilities, and premature death. Despite the relatively small number of individuals living with SCD, the healthcare system does not have a consistent method to capture the data necessary to address these individuals' complex health challenges

and connect them to comprehensive care. The Division's Sickle Cell Data Collection Program has been critical in collecting and analyzing longitudinal data about people living in the U.S. with SCD. This program currently covers 16 states (approximately 50% of the SCD population in the U.S.) and has been instrumental to ensuring individuals living with this disease to receive adequate care and treatment. The Division's sickle cell data collection, outreach and education programs are necessary to help healthcare professionals understand the effects of medical interventions and inform best practices for SCD, as well as establish cost-effective practices to improve and extend the lives of individuals with SCD.

- Each year, 100,000 people die from blood clots, or 274 people each day on average. While blood clots do not respect age, gender, race or ethnicity, certain people are at greater risk than others. Many blood clots can be prevented, a major focus of CDC's Blood Disorders Division, which is done by the Division's oversight of critical blood clot education and awareness efforts. Needless death and disability could be avoided by vigorous application of known public health measures. However, the elimination of this Division will limit CDC's ability to promote the use of these effective prevention techniques with devastating risks of increased death and disability and higher healthcare spending.
- Inherited bleeding disorders such as hemophilia and von Willebrand disease present complex, lifelong challenges for affected individuals and their families: internal bleeding, joint damage, permanent disability, or even death. The Division drives critical life- and cost-saving advances in care and prevention for people with these conditions and supports blood and blood product safety monitoring activities of national importance. The Division's work traces back to the 1980s' tainted blood crisis, when an estimated 90% of the U.S. hemophilia population contracted HIV and/or hepatitis C through the use of plasma-derived clotting factor products. CDC investigators were the first to discern and warn of HIV's transmissibility through blood. To this day, the Division of Blood Disorders serves the bleeding disorders community and the nation at large through its public health surveillance activities – including maintaining a laboratory with blood samples dating back to 1996 to which additional samples are added still today. The Division also funds the collection and dissemination of key data on bleeding disorders through the collaborative "Community Counts" program and supports educational outreach to increase patient and provider understanding of hemophilia and its complications. Recently, the CDC's work has focused on improving knowledge about and prevention of inhibitors – a devastating and expensive complication of hemophilia that vastly increases the burden of disease and costs of treatment.
- Thalassemia (or Cooley's anemia), in its most severe form, requires patients to undergo biweekly blood transfusions (usually beginning at age two) followed by daily iron chelation to remove excess iron from the heart, liver and other organs. CDC's work in thalassemia continues to provide vital educational information and programs both for individuals with thalassemia and medical providers. The elimination of the Division would end this critical avenue for educating medical providers about treating thalassemia, which requires a multidisciplinary approach and an understanding of how treatment challenges change over the course of a patient's lifetime. CDC also just recently funded a National Academies of Sciences, Engineering, and Medicine study to provide a "big picture" look at thalassemia; without it, sparse resources will be spread thin, rather than being utilized in a constructive, strategic manner to improve treatment for patients across the thalassemia syndromes.

As you can see, chronic and acute blood disorders have a major public health impact, an impact that can continue to be significantly reduced by the critical work of DBDPHG. This Division's impact on patient care, research, and public health cannot be overstated. The work of this Division must not only continue but be reinforced.

The undersigned organizations implore you to act immediately to reinstate the Division and safeguard the health of millions of Americans living with blood disorders.

Sincerely,

Alaska Hemophilia Association
American Society for Clinical Pathology
American Society of Hematology
American Society of Pediatric Hematology/Oncology
American Thrombosis and Hemostasis Network (ATHN)
Arizona Bleeding Disorders
Association of Public Health Laboratories
Bleeding Disorders Alliance Illinois
Bleeding Disorders Alliance of North Dakota
Bleeding Disorders Association of Northeastern New York
Bleeding Disorders Association of South Carolina
Bleeding Disorders Coalition of Florida
Bleeding Disorders Foundation of North Carolina
Bleeding Disorders of the Heartland
Bridges Pointe, Inc.
Cayenne Wellness Center
CHES, Foundation
Cooley's Anemia Foundation
Discovering Moorer2Life
Foundation for Women & Girls with Blood Disorders
Gateway Hemophilia Association
Great Lakes Hemophilia Foundation
Greater Ohio Bleeding Disorders Foundation
Hemophilia Alliance
Hemophilia Association of New Jersey
Hemophilia Association of San Diego County
Hemophilia Association of the Capital Area
Hemophilia Council of California
Hemophilia Federation of America
Hemophilia Foundation of Maryland
Hemophilia Foundation of Michigan
Hemophilia Foundation of MN/SD
Hemophilia Foundation of Northern California
Hemophilia Foundation of Southern California
Hemophilia of Georgia
Hemophilia of Indiana

Little Hercules Foundation
Lone Star Bleeding Disorders Foundation
Louisiana Hemophilia Foundation
Martin Center Sickle Cell Inc
Mary M. Gooley Hemophilia Center
Maryland Sickle Cell Disease Association
Midwest Hemophilia Association
Mountain States Regional Hemostasis Network
MTS Sickle Cell Foundation, Inc.
National Bleeding Disorders Foundation
National Bleeding Disorders Foundation Colorado Chapter
National Blood Clot Alliance
Nevada Chapter, National Bleeding Disorders Foundation
New England Hemophilia Association
New York City Hemophilia Chapter
New York State Bleeding Disorders Coalition
Northwest Ohio Hemophilia Foundation
Novant Health HTC
Ohio Bleeding Disorders Council
Oklahoma Hemophilia Foundation
Pacific Northwest Bleeding Disorders
Piedmont Health Services and Sickle Cell Agency
Rainbow Baby and Children's Hospital Hemophilia Treatment Center
Rocky Mountain Hemophilia & Bleeding Disorders Association
Sangre de Oro, Inc.
Sickle Cells
Sickle Cell Anemia Foundation of Oregon and P.N. West
Sickle Cell Anemia Resource Foundation
Sickle Cell Assn of Texas Marc Thomas Foundation
Sickle Cell Consortium
Sickle Cell Council of New Mexico, Inc.
Sickle Cell Disease Association of America - Central Alabama Chapter
Sickle Cell Disease Association of America Miami-Dade County Chapter
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 Warriors of Wisconsin
Snake River Hemophilia and Bleeding Disorders, Associate
Southeast Alabama Sickle Cell Association Inc. (SEASCA)
Southwestern Ohio Hemophilia Foundation

St. Jude Affiliate Clinic at Novant Health Hemby Children's Hospital- Pediatric Hemophilia Treatment Center
Supporters of Families with Sickle Cell Disease, Inc.
Tennessee Hemophilia and Bleeding Disorders Foundation
Texas Bleeding Disorders Coalition
The Coalition for Hemophilia B
The Hemophilia Association of New York
The National Medical Association
The Sickle Cell Association Of New Jersey
Tri-State Bleeding Disorder Foundation
United States Hemophilia Treatment Center Network
Uriel E. Owens Sickle Cell Disease Association of the Midwest
Utah Hemophilia Foundation
Virginia Hemophilia Foundation
Western New York Bloodcare
Western Pennsylvania Bleeding Disorders Foundation

Cc:

- The Honorable Bill Cassidy, MD, Chair, Senate Health, Education, Labor, and Pensions Committee
- The Honorable Bernie Sanders, Ranking Member, Senate Health, Education, Labor, and Pensions Committee
- The Honorable Susan Collins, Chair, Senate Committee on Appropriations
- The Honorable Patty Murray, Ranking Member, Senate Committee on Appropriations
- The Honorable Tom Cole, Chair, House Committee on Appropriations
- The Honorable Rosa DeLauro, Ranking Member, House Committee on Appropriations
- The Honorable Brett Guthrie, Chair, House Energy and Commerce Committee
- The Honorable Frank Pallone, Ranking Member, House Energy and Commerce Committee