

June 15, 2017

The Honorable Tom Cole
Chairman
Appropriations Subcommittee on Labor,
Health and Human Services, Education and Related Agencies
U.S. House of Representatives Washington, DC 20515

The Honorable Rosa DeLauro
Ranking Member
Appropriations Subcommittee on Labor,
Health and Human Services, Education and Related Agencies
U.S. House of Representatives Washington, DC 20515

Dear Chairman Cole and Ranking Member DeLauro:

The undersigned organizations represent millions of Americans with different blood-related disorders that can cause lifetime disability and early death, and significantly impact the cost of healthcare in this country. For example, preventable thrombosis related conditions cost the healthcare system at least \$10 billion every year. Blood disorders in the United States are a substantial public health problem that require a strong federal response and effective partnerships with affected patients and their families. The Centers for Disease Control and Prevention (CDC) is the primary federal agency responsible for addressing the impact of these conditions on the general public's health.

We strongly oppose the reductions in CDC funding proposed by the President in his fiscal year 2018 budget. In particular, we strongly object to the \$35.4 million reduction proposed to the budget for CDC's National Center for Birth Defects and Developmental Disabilities (NCBDDD). This Center is the home for the Division of Blood Disorders, the only federal agency that works directly with states, patients and families to reduce the impact of thrombosis and thrombophilia, hemophilia, sickle cell disease (SCD) and thalassemia, to name some of the key programmatic areas. While the White House budget documents do not indicate what portion of the \$35 million reduction to the NCBDDD budget will apply to the Blood Disorders Division, it is hard to believe that this important office will remain unaffected if this budget proposal is adopted by Congress.

While each blood disorder affects a particular segment of the US population, and has unique characteristics, there are many common threads that magnify their overall impact on the healthcare system and affected individuals. For example, each of these blood disorders can cause permanent disability. Early death is a common result for these affected individuals when compared to the general population. In addition, the presence of one of these blood disorders can be a risk factor for another disorder. For example, people with SCD are more likely to have dangerous blood clots than the general population. Thalassemia patients suffer from heart and liver damage, as well as early onset osteoporosis. Therapies can be extremely expensive, causing financial pain for even the most well-insured individuals and families.

Current funding for the Division of Blood Disorders is only \$14.8 million, a number that has not kept pace with medical need or inflation. To inflict further reductions as proposed by the President would cause significant disruption in these important public health efforts. At a minimum, the funding level should be retained at current levels, although an increase is well past due.

Blood clots affect approximately one million Americans annually. 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. For example, pregnant women, women receiving hormonal therapy for menopause and women using estrogen based birth control are at increased risk. Cancer patients are at higher risk from blood clots. Age is also a risk factor, so the aging population in the United States will only increase the potential for more blood clots, with resulting disability and premature death.

Many blood clots can be prevented, a major goal of CDC's Blood Disorders Division. Needless death and disability could be avoided by vigorous application of known public health measures. However, a major reduction in blood disorders spending will limit CDC's ability to promote the use of these effective prevention techniques. The only results will be increased death and disability and higher healthcare spending.

SCD is an inherited, lifelong disorder affecting nearly 100,000 Americans. Individuals with the disease produce abnormal hemoglobin which results in their red blood cells becoming rigid and sickle-shaped and causing them to get stuck in blood vessels and block blood and oxygen flow to the body. SCD complications include severe pain, stroke, acute chest syndrome, organ damage, and in some cases premature death. Though new approaches to managing SCD have led to improvements in diagnosis and supportive care, many people living with the disease are unable to access quality care and are limited by a lack of effective treatment options. CDC's SCD surveillance, 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.

Thalassemia (or Cooley's anemia), in its most severe form, requires patients to undergo biweekly blood transfusions (usually beginning at age 2) followed by daily iron chelation to remove excess iron from the heart, liver and other organs. As the largest users of red blood cells, these patients are generally the first to be impacted by emerging blood-borne infections, information that CDC surveillance of the blood supply can identify and protect the general public.

Bleeding disorders are largely genetic disorders that impair the body's ability to clot properly. People with hemophilia rely on prescription clotting factor medication to avoid painful or potentially life threatening internal bleeding episodes that can lead to advanced medical issues such as joint and muscle damage. People with hemophilia are also at risk of developing an "inhibitor," or an immune system response that destroys clotting factor. Patients with inhibitors require an increase in factor dosing (both units and frequency); experience increased pain and health complications, resulting in additional hospitalizations and days missed from work and school; and bear increased costs. Much is still unknown about who is prone to developing inhibitors, how inhibitors develop, or how they can be prevented. Through the Community Counts Registry for Bleeding Disorder Surveillance, the NCBDDDD has provided the first ever estimates of the burden of inhibitors among those living with hemophilia. This surveillance is vital to the continued treatment of a complication that has a severe and prolonged effect on inhibitor patients' quality of life and healthcare costs.

In conclusion, blood disorders have a major public health impact, an impact that can be reduced if the Division is adequately funded. However, the likelihood of progress under the President's proposed budget is nil.

The undersigned organizations strongly urge you and your Congressional colleagues to reject the proposed cuts to CDC funding, particularly for the blood disorders programs in NCBDDDD. With your support, we can maintain the progress to reduce the health impacts of blood disorders.

Sincerely,

American Society of Hematology
Cooley's Anemia Foundation
CureHHT
Hemophilia Federation of America
National Blood Clot Alliance
National Hemophilia Foundation
Sickle Cell Disease Association of America

Cc: Representative Andy Harris, MD
Representative Barbara Lee
Representative Chuck Fleischmann
Representative Jaime Herrera Beutler
Representative John Moolenaar
Representative Katherine Clark
Representative Lucille Roybal-Allard
Representative Mark Pocan
Representative Martha Roby
Representative Mike Simpson
Representative Steve Womack