PROTECTING PEOPLE
and Preventing Complications of Blood Disorders

CDC’s National Center on Birth Defects and Developmental Disabilities (NCBDDD) works to reduce the public health burden resulting from blood disorders by contributing to a better understanding of blood disorders and their complications.

Blood disorders affect millions of people in the United States. Many of these disorders and their complications could be avoided with proper preventive actions and early intervention. We are dedicated to helping people with blood disorders by

- Contributing to a better understanding of blood disorders and their complications;
- Working to develop, implement, and evaluate prevention programs;
- Helping consumers and healthcare providers get the information that they need; and
- Encouraging action to improve the quality of life for people living with or affected by these conditions.

Accomplishments

- Supported, developed, and promoted a supplement to the journal, Journal of Hospital Medicine, on venous thromboembolism (VTE) titled “Preventing Hospital-Acquired Venous Thromboembolism: Lessons from the Field.” The executive summary within the supplement described the partnerships between CDC, the Joint Commission Center for Transforming Healthcare, and the Agency for Healthcare Research and Quality to advance patient safety by improving the prevention of healthcare-associated VTE.
- The remaining articles highlighted best practices and strategies for prevention of healthcare-associated VTE within five hospitals.
These hospitals were the 2015 CDC Healthcare-Associated VTE Prevention Challenge Champions.

- Coordinated a CDC Public Health Grand Rounds titled “Improving the Lives of People with Sickle Cell Disease,” which featured a panel of four leaders in the field of sickle cell disease (SCD). Speakers discussed the importance of access to and use of healthcare services by people with SCD as key to decreasing illness and death. They discussed how CDC’s Sickle Cell Data Collection Program provided important population-level information about how SCD progresses in people, the influence of interventions and use of healthcare services on improving health and quality of life for people with SCD, and the frequency of premature death from the condition.

- Worked with the National Hemophilia Foundation to launch “Better You Know,” a public health education campaign to increase awareness about the signs, symptoms, and diagnosis of bleeding disorders among women. The campaign provided information for healthcare providers and women experiencing heavy menstrual bleeding who may be at risk for having a bleeding disorder. The campaign website has an online questionnaire, tools to help women determine their risk for a bleeding disorder, and next steps to seek care.

- Coordinated the development of a four-module educational video series designed to help healthcare providers reduce the complications of blood transfusion when treating patients with SCD. Georgia State University and Emory University developed this video series. Continuing medical and nursing education credits are available for each module.
Looking to the Future

NCBDDD will continue to learn about factors that place people with hemophilia at risk for inhibitors and other complications. We will study and promote the use of periodic inhibitor testing, monitor complications from blood and treatment products, and research how well treatment strategies prevent disease-related complications. We will work to prevent blood clots and improve laboratory techniques to identify factors that put people at risk for VTE. Health education, early detection, and medical referrals will remain part of this important work. We strive to better identify people living with thalassemia and sickle cell disease and better understand complications from blood transfusions.

Notable Scientific Publications


Srivasht S, et al. Differences in Bleeding Phenotype and Provider Interventions in Postmenarchal Adolescents When Compared to Adult Women with Bleeding Disorders and Heavy Menstrual Bleeding. Haemophilia. 2017 Sep 5. [Epub ahead of print]
SPOTLIGHT ON:

American Society of Hematology & National Blood Clot Alliance

People with blood disorders are living longer than ever before, but with far too many medical complications that could be prevented. These complications have serious, sometimes fatal, health consequences and cost our healthcare system billions of dollars every year. CDC’s National Center on Birth Defects and Developmental Disabilities (NCBDDD) invests in activities that increase understanding of blood disorders, advance medical care and treatments, and improve outcomes for all people with blood disorders.

Sickle Cell Disease

The American Society of Hematology (ASH), an organization representing over 17,000 members dedicated to the study and treatment of blood and blood-related diseases and disorders, is committed to addressing the burden of sickle cell disease (SCD) and is undertaking a multi-faceted initiative to improve outcomes for individuals with the disease, both in the United States and globally. Activities include convening the Sickle Cell Disease Coalition (SCDC), developing up-to-date guidelines describing the management of acute and chronic complications of SCD, and educating hematologists and other healthcare providers in all settings to properly respond to SCD complications in their everyday practices.

NCBDDD and ASH worked collaboratively along with the Sickle Cell Disease Association of America to develop a Sickle Cell Trait Toolkit—a collection of resources to increase understanding of trait. CDC’s Sickle Cell Data Collection (SCDC) program in California and Georgia continues to inform the ASH initiative by providing critical information on individuals with SCD over time, identifying major gaps in diagnosis, treatment, and healthcare access for people with SCD. CDC has also helped support the Society’s efforts to raise awareness and education of the disease.

Venous Thromboembolism

The National Blood Clot Alliance (NBCA) is a 501(c)(3), non-profit, voluntary health organization dedicated to advancing the prevention, early diagnosis, and successful treatment of life-threatening blood clots. NBCA accomplishes its mission through programs that build public awareness, educate patients and healthcare professionals, and promote supportive public and private sector policy.

About 900,000 people are affected by blood clots each year, and 100,000 of these individuals will die due to a blood clot, which is more than the number of people who die each year due to AIDS, breast cancer, and motor vehicle crashes combined.

Launched in 2015, NBCA’s Stop the Clot, Spread the Word™ campaign has reached more than 167 million people and is made possible through funding provided by the CDC. The centerpiece of the Stop the Clot, Spread the Word™ campaign involves a dedicated educational web portal that houses a suite of venous thromboembolism (VTE) educational tools, including videos, infographics, and downloadable checklists that people can review and share with their healthcare professionals. This important partnership between NBCA and CDC continues, and the program will expand to include information specific to other VTE risk groups and more high-profile public awareness activities, reaching more than 500 million people in the next two years.

NCBDDD’s Blood Disorders Topics

- Hemophilia
- Sickle Cell Disease
- Thalassemia
- Venous Thromboembolism
- Vitamin K Deficiency Bleeding
- Von Willebrand Disease

Visit www.cdc.gov/ncbddd to learn more.