

National Center on Birth Defects and Developmental Disabilities Annual Report Fiscal Year 2015



PROTECTING PEOPLE AND PREVENTING COMPLICATIONS OF BLOOD DISORDERS

CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD) made significant progress in identifying inhibitors in people with hemophilia, raising awareness of venous thromboembolism and learning more about sickle cell disease.

Blood disorders - such as deep vein thrombosis, hemophilia, and thalassemia - affect millions of people each year. Men, women, and children of all backgrounds live with the complications of these conditions, many of which are painful and potentially life-threatening. NCBDDD works to reduce the public health burden of blood disorders by contributing to a better understanding of blood disorders and their complications; developing, implementing and evaluating prevention programs; providing information to consumers and health professionals; and working to improve the quality of life for people living with these conditions.



Accomplishments

- Contributed to new inhibitor testing guidelines issued by the National Hemophilia Foundation's Medical and Scientific Advisory Council based on the results of the CDC's Hemophilia Inhibitor Research Study. The guidelines state that everyone with hemophilia should be tested for inhibitors at least once every year. However, some people with hemophilia may need to be tested more frequently, depending on the severity of the disease and other risk factors. CDC's monitoring program, called Community Counts, is now offering annual inhibitor testing for participants at no cost to Hemophilia Treatment Centers (HTCs).
- Received over 500 CHOICE (Community Having Opportunity to Influence Care Equity) surveys from people with hemophilia and other bleeding disorders. CHOICE is a collaborative project with Hemophilia Federation of America to learn more about health outcomes and care equity of all members of the bleeding disorders community. The CHOICE survey asked questions about diagnosis, bleeding history, treatment, insurance coverage, quality of life, and quality of care. The knowledge gained from the CHOICE survey will be used to help change lives, improve medical care, and help ensure access to the services that people with bleeding disorders need.
- Announced the launch of the HHS Competes Healthcare-Associated Venous Thromboembolism (HA-VTE) Prevention Challenge to identify best practices and increase the use of strategies to prevent healthcare-associated blood clots.
- Raised awareness of risk factors for venous thromboembolism (VTE), reaching an audience of over 70 million, by supporting the National Blood Clot Alliance's *Stop the Clot, Spread the Word™* awareness campaign. The campaign included a digital media press release, web portal, and a VTE infographic which appeared in over 900 online television, radio, and newspaper websites.

- Partnered with the CDC Foundation to build public private partnership support to develop a longitudinal data collection system for sickle cell disease (SCD). This is the first system to potentially collect information on every American diagnosed with SCD. The system will collect information on the geographic distribution of patients and providers, transition of (or change in) care from pediatric to adult providers, Hispanic patients with SCD, older patients with SCD, and high usage of healthcare services for SCD. By linking data from multiple sources, the system will allow for unique insight into the course of the disease and the burden of its effects on public health.

Looking to the Future

NCBDDD's Division of Blood Disorders (DBD) will continue its work to determine the causes and risk factors for developing inhibitors in people with hemophilia. DBD will evaluate and promote the use of periodic inhibitor screening, monitor complications from blood and treatment products, and assess the effectiveness of strategies to prevent disease-related complications. We will remain focused on HA-VTE prevention; improving laboratory techniques; and increasing provider and public knowledge and awareness of the signs and symptoms of blood disorders, the importance of early recognition and diagnosis, and referrals to specialists and comprehensive care. DBD will improve the understanding of complications of blood transfusions used to treat people with thalassemia and sickle cell disease. We will work to improve the health of individuals with blood disorders over the lifespan.

Notable Scientific Publications

Boylan B, et al. Evaluation of von Willebrand factor phenotypes and genotypes in Hemophilia A patients with and without identified F8 mutations. *J Thromb Haemost* 2015 Jun;13(6):1036-42.

Faiz AS, et al. Characteristics and risk factors of cancer associated venous thromboembolism. *Thromb Res* 2015 Sept;136(3):535-41.

Hulihan MM, et al. State-based surveillance for selected hemoglobinopathies. *Genet Med* 2015 Feb;17(2):125-30.

Lewis DA, et al. Whole blood gene expression profiles distinguish clinical phenotypes of venous thromboembolism. *Thromb Res* 2015 Apr;135(4):659-65.

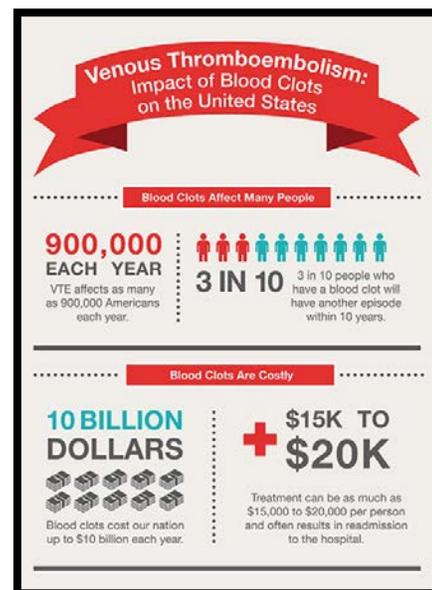
Mainous AG 3rd, et al. Attitudes toward management of sickle cell disease and its complications: a national survey of academic family physicians. *Anemia* 2015; 2015:1-6.

Miller CH, et al. Characteristics of hemophilia patients with factor VIII inhibitors detected by prospective screening. *Am J Hematol* 2015 Jul;90:871-6.

Tsai J, et al. Determinants of venous thromboembolism among hospitalizations of US adults: a multilevel analysis. *PLoS One* 2015 Apr;10(4):1-15.

Walsh CE, et al. Impact of inhibitors on hemophilia A mortality in the United States. *Am J Hematol* 2015 May;90(5):400-5.

Wendelboe AM, et al. The design and implementation of a new surveillance system for venous thromboembolism using combined active and passive methods. *Am Heart J* 2015 Sept;170(3):447-54.



Spotlight on: National Blood Clot Alliance

This Spotlight was contributed by Randy Fenninger, JD, who is CEO for the National Blood Clot Alliance.

The National Blood Clot Alliance (NBCA) works to reduce death and disability caused by blood clots, one of the most common blood disorders addressed by the Centers for Disease Control and Prevention's (CDC's) National Center on Birth Defects and Developmental Disabilities.

This work is important because approximately 900,000 Americans experience a blood clot every year and 100,000 deaths result. In the United States about \$10 billion is spent to treat these clots and their consequences. The tragedy of blood clots is that the majority of them could be prevented or treated promptly to avoid death or injury.

NBCA works to address this challenge through public awareness campaigns, patient education efforts, and health professional training. Currently, NBCA is working with CDC on year 2 of a 5 year cooperative agreement to build broad public awareness about blood clots, with special focus on at-risk populations, such as pregnant women, hospitalized patients, and cancer patients. In year one, just completed in September, public awareness messages reached an estimated audience of more than 70 million people. NBCA recently launched a separate education program for women, highlighting estrogen as a risk factor for blood clots (for example, an increased risk during pregnancy or while using hormone therapy during menopause).

Our public outreach has direct results. Each day we receive calls and emails from individuals who need help for themselves or a family member because of blood clots. Frequently they need information on how to get better care for a blood clot. We maintain a nationwide registry of specialists, and are often able to guide them to the expert care they need for their condition. Their gratitude is expressed in many ways, but the most important is to receive a call or email of thanks after they have been treated successfully.

To view the annual report online, please visit:
www.cdc.gov/ncbddd/aboutus/annualreport2015

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