Blood disorders affect millions of people each year in the United States, cutting across the boundaries of age, race, sex, and socioeconomic status. With proper actions, some blood disorders can be prevented. In the case of inherited blood disorders, early intervention can prevent serious complications. At CDC, 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 they need; and
- Encouraging action on behalf of individuals living with, or affected by, blood disorders.

**Accomplishments**

- Released new resources and potentially lifesaving information, through the CDC-funded *Stop the Clot, Spread the Word*™ campaign on the risks, signs, and symptoms of blood clots among women who are pregnant or recently gave birth. These educational resources empower women to talk with their healthcare providers about the factors that increase their risk for blood clots as well as determine if they might benefit from a plan to prevent blood clots. The previous components of the campaign, which provide general information about blood clots and their risks related to hospitalization, have already achieved more than 300 million media impressions.

- Published key articles and reports using Community Counts data:
  - Community Counts: *Evolution of a National Surveillance System for Bleeding Disorders*, an article that describes the project’s organization and components and provides a summary of patients enrolled through the end of September 2017.
  - *The 2014 Community Counts Registry Report*, a report that describes the project background, methods, and select baseline data collected during the project’s first year.
  - Community Counts: *The HTC Population Profile Data through March 2018*, a report that contains a set of 12 data items collected on patients with
bleeding disorders or venous thromboembolism (blood clots) who receive care at U.S. hemophilia treatment centers.

• Conducted a CNE/CME-accredited webinar titled “Improving Outcomes for Females with Bleeding Disorders in Non-Hematology Healthcare Settings.” This webinar, funded through a cooperative agreement between the National Hemophilia Foundation and the Division of Blood Disorders, is intended to
  - Help raise awareness among healthcare providers who are not blood disorders specialists about bleeding disorders in women and how best to care for these women;
  - Encourage provider collaboration with hemophilia treatment centers;
  - Influence clinical practice;
  - Reduce reproductive system-related diseases in women; and
  - Improve health outcomes.

• Worked with partners to produce or collaborate on numerous education and outreach materials through the Sickle Cell Data Collection (SCDC) program including:
  - The Bloodline: the SCDC Program quarterly newsletter;
  - SCDC Program Report: Data to Action;
  - California SCDC webinars; and
  - Videos for individuals with sickle cell disease who are transitioning from pediatric to adult care.

• Developed educational materials, published research articles, and captured personal stories about therapeutic blood transfusions for hemoglobinopathies (thalassemia and sickle cell disease), including:
  - An animated graphic about blood donations among racial/ethnic minorities;
  - An article describing a novel intervention in the primary care setting to improve management of transfusion-related iron overload; and
  - A personal story about Maria Hadjidemetriou’s journey living with thalassemia, which includes her advice for others living with inherited blood disorders.
PROTECTING PEOPLE

Looking to the Future

NCBDDD’s important work will continue to include activities that increase understanding of blood disorders, advance medical care and treatments, and improve outcomes for all people with blood disorders by promoting health education, early detection, and medical referrals for this population. For thalassemia and sickle cell disease, NCBDDD invests in determining the number, health needs, and healthcare use of people living with these types of blood disorders. NCBDDD also works to understand more fully the complications resulting from blood transfusions. For those living with hemophilia, NCBDDD is researching how well treatment strategies are preventing disease-related complications, as well as learning the factors that place people with hemophilia at risk for inhibitors and other complications and studying and promoting the use of periodic inhibitor testing. NCBDDD also monitors complications arising from the use of blood products and new and existing treatment products; seeks to prevent blood clots; and works to improve laboratory techniques used to identify those at risk for clots.

Notable Scientific Publications


National Hemophilia Foundation

The National Hemophilia Foundation (NHF) is committed to preventing the complications associated with hemophilia and other bleeding disorders. As part of NHF’s cooperative agreement with CDC, NHF has focused on preventing joint damage for those living with a bleeding disorder. In 2017, NHF launched educational activities to encourage the community to “Make Your Move” through increased safe physical activity. In addition, NHF has

• Updated and revised its Playing It Safe guide (available in English and Spanish);
• Updated and revised its ratings on safe physical activities;
• Launched multiple Make Your Move webinars led by physical therapists promoting safe increased activity; and
• Continued educating the community through in-person workshops that bleeding disorders chapters around the country can bring to their local education events.

Through these efforts (distributed print materials, webinar views, workshop attendees, and website page views), NHF has garnered more than 17,000 touchpoints. To ensure better outreach to Spanish-speaking communities, NHF launched its Guías Culturales program, which trained nine Spanish-speaking community members in the TIPs to Improve Communication with Healthcare Providers workshop to facilitate local bleeding disorders events in Spanish and help address some of the cultural barriers faced when trying to get care for a bleeding disorder and prevent its complications.

NCBDDD’s Blood Disorders Topics

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

Visit [www.cdc.gov/ncbddd](http://www.cdc.gov/ncbddd) to learn more.