

# National Center on Birth Defects and Developmental Disabilities

Annual Report | Fiscal Year 2013



## Protecting People and Preventing Complications of Blood Disorders



[Blood disorders](#) are a serious public health problem affecting millions of Americans, yet we don't have an accurate picture of the real impact of these conditions. CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD) is uniquely positioned to reduce the public health burden resulting from these conditions by contributing to a better understanding of blood disorders and their complications. We ensure that information is accessible to consumers and health care providers. We encourage the use of information to inform actions that improves the quality of life for people living with or affected by these conditions.

### Video: A Look at Hemophilia

Centers for Disease Control and Prevention  
National Center on Birth Defects and  
Developmental Disabilities  
Division of Blood Disorders:  
A Look at Hemophilia  
Building a Better Tomorrow

[Watch this video](#) to learn about hemophilia and CDC's work.

### Budget

[Learn more about budget](#)

[Learn more about state funding](#)

### Accomplishments

- Launched a [new database of more than 1,000 Factor IX \(Factor 9\) gene mutations](#) reported to cause hemophilia B. The new database supplements CDC's Hemophilia A Mutation Project (CHAMP), a database of more than 2,000 Factor VIII (Factor 8) gene mutations reported to cause hemophilia A. This information can be used to determine

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which hemophilia mutations may increase the risk of developing an inhibitor (antibody) which lessens the effectiveness of hemophilia treatment.

- Worked with partners to launch surveillance of [inhibitors](#), a significant complication of treatment in [hemophilia](#). Inhibitors will be monitored through centralized testing at CDC. NCBDDD's blood disorders laboratory developed new methods to test patients as well as new ways to confirm the results. The surveillance will result in the first estimates of the incidence and prevalence of inhibitors among people with hemophilia in the United States.
- Worked to decrease death and disability from venous thromboembolism (VTE) through health education and outreach. NCBDDD launched an expert video commentary series on Medscape, titled Blood Clots and Long Distance Travel: Advising Patients. NCBDDD authored a [chapter on blood clots and travel](#) in CDC's Yellow Book and presented a Public Health Grand Rounds, "[Preventing Venous Thromboembolism](#)," which addressed what is known about how to reduce the rate of hospital-associated VTE.
- Published an investigation of a cluster of late [vitamin K deficiency bleeding \(VKDB\)](#) in infants. NCBDDD developed a comprehensive communications and outreach plan, developed a fact sheet, "[Protect Your Baby from Bleeds - Talk to Your Healthcare Provider about Vitamin K](#)," created a podcast, "[Talk with Expectant Parents about Late Vitamin K Deficient Bleeding Among Infants](#)," and released a [Medscape Commentary](#) on VKDB.



**PROTECTING PEOPLE  
AND PREVENTING COMPLICATIONS  
OF BLOOD DISORDERS**

**1 IN 10**

**WITH A BLOOD CLOT  
WILL DIE IF IT MOVES  
TO THE LUNGS**

Healthcare costs associated with blood clots in the U.S. are

 **\$10  
BILLION**  
or more each year

Preventing readmission due to a blood clot can **save an average of**

**\$15,000**

 in hospital costs per patient

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- Convened an expert panel to get stakeholder feedback on gaps in prevention research across blood disorders and identify priority areas for intervention research, implementation, and evaluation. A summary of this meeting has been developed and submitted to a special supplement of the American Journal of Preventive Medicine.
- As a result of NCBDDD's Registry and Surveillance for Hemoglobinopathies surveillance pilot project, California initiated population-based surveillance for [thalassemia](#). A newly-established committee is using the surveillance data to create fact sheets that educate Californians about the incidence of thalassemia in their state.
- Launched a Blood Safety Surveillance System among people with blood disorders to identify complications and infectious transmissions in heavily transfused populations such as those with thalassemia and [sickle cell disease](#) to keep the blood supply safe for everyone.

### Looking to the Future

NCBDDD's Division of Blood Disorders is committed to serving those with inherited (hemophilia, thalassemia and sickle cell disease) as well as acquired (VTE) blood disorders. Collaborating with our many public health partners – other federal and state agencies, academia, and professional and community-based organizations – NCBDDD's Division of Blood Disorders improves the lives of people at risk or affected by blood disorders. Emerging issues in each of our priority areas include ensuring that evidence-based interventions are put into practice to improve health outcomes for the populations we serve. For example, among people with severe hemophilia, the overall proportion of people regularly using factor

#### Did You Know?

- 60,000-100,000 Americans die of deep vein thrombosis/pulmonary embolism each year.<sup>1</sup>
- Sickle cell disease affects an estimated 90,000 to 100,000 Americans.<sup>2</sup>
- A CDC study showed that people with hemophilia were at risk for developing an inhibitor, which is currently the most serious complication of hemophilia care.<sup>3</sup>

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treatment products to prevent bleeding episodes (the only evidence-based prevention strategy for joint disease) rose from 34% in 2004 to only 45% in 2009 and it is estimated that fewer than 50% of hospitalized patients receive risk-appropriate prevention for VTE.

### Notable 2013 Scientific Publications

Landi D, et al. [Characteristics of abdominal vein thrombosis in children and adults.](#) Thrombosis and Haemostasis. 2013 Apr;109(4):625-632.

Miller CH, et al. The Hemophilia Inhibitor Research Study Investigators. [Comparison of clot-based, chromogenic, and fluorescence assays for measurement of factor VIII inhibitors in the U.S.](#) Hemophilia Inhibitor Research Study. Journal of Thrombosis and Haemostasis. 2013;11: 1300–1309.

Payne AB, et al. [Invasive pneumococcal disease among children with and without sickle cell disease in the United States, 1998-2009.](#) The Pediatric Infectious Disease Journal. 2013 Dec;32(12):1308-1312.

Payne AB, et al. [The CDC Hemophilia A Mutation Project \(CHAMP\) mutation list: a new online resource.](#) Human Mutation. 2013 Feb;34(2):E2382-E2392.

Simmons GM, et al. [Identifying information needs among children and teens living with haemophilia.](#) Haemophilia. 2014 Jan;20(1):1-8. Epub 2013 Jun 28

Soucie JM, et al. [Evidence for the transmission of parvovirus B19 in patients with bleeding disorders treated with plasma-derived factor concentrates in the era of nucleic acid test \(NAT\) screening.](#) Transfusion. 2013; 53:1217-1225.

Vichinsky E, et al. [Transfusion complications in thalassemia patients: a report from the Centers for Disease Control and Prevention.](#) Transfusion. 2014 Apr;54(4):972-981. Epub 2013 Jul 25.

Wang WC, et al. [Hydroxyurea is associated with lower costs of care of young children with sickle cell anemia.](#) Pediatrics. 2013 Oct;132(4):677-683.

Wang Y, et al. [Sickle cell disease incidence among newborns in New York State by maternal race/ethnicity and nativity.](#) Genetics in Medicine. 2013 Mar;15(3):222-228.

Yusuf HR, et al. [Hospitalizations of adults  \$\geq 60\$  years of age with venous thromboembolism.](#) Clinical and Applied Thrombosis/Hemostasis. 2014 Mar;20(2):136-142. Epub 2013 Jun 27.

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### References

1. Beckman MG, Hooper WC, Critchley SE, Ortel TL. Venous thromboembolism: a public health concern. Am J Prev Med. 2010 Apr;38(4 Suppl):S495-S501.
2. National Heart, Lung, and Blood Institute. Disease and conditions index. Sickle cell anemia: who is at risk? Bethesda, MD: US Department of Health and Human Services, National Institutes of Health, National Heart, Lung, and Blood Institute; 2009. Available from: [http://www.nhlbi.nih.gov/health/dci/Diseases/Sca/SCA\\_WholsAtRisk.html](http://www.nhlbi.nih.gov/health/dci/Diseases/Sca/SCA_WholsAtRisk.html)
3. Soucie JM, Miller CH, Kelly FM, Payne AB, Creary M, Bockenstedt et al. A study of prospective surveillance for inhibitors among persons with haemophilia in the United States. Haemophilia. 2014;20:230-237.

**To view the annual report online, please visit:**

<http://www.cdc.gov/ncbddd/aboutus/annualreport2013>

**For more information, please visit:**

<http://www.cdc.gov/ncbddd>