

1 in 76 Americans

are affected by a blood disorder.

People with blood disorders are living longer than ever before, but with far too many medical complications that could be prevented. These conditions 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.

How NCBDDD makes a difference

Hemophilia Treatment Centers – NCBDDD works with funded partners to implement the Community Counts project in hemophilia treatment centers (HTCs) across the United States, raising participation among all 136 federally-funded HTCs (as of July 31, 2016) to 100% for the HTC Population Profile, 92% for the Registry for Bleeding Disorders Surveillance, and 91% for Mortality Reporting.

Public Health Approach to Blood Disorders – NCBDDD recognized and shared best practices on preventing blood clots in hospitalized patients. NCBDDD supported and coordinated the development of a publication highlighting the public health impacts of SCD on patients, healthcare providers, and healthcare systems, and work being done to improve the lives of people living with SCD.

Hemophilia – NCBDDD supports inhibitor testing as part of the Community Counts Registry for Bleeding Disorders Surveillance, and provided the first-ever estimates of the burden of inhibitors among people in the United States with hemophilia. An inhibitor is a potentially serious health problem affecting people with bleeding disorders that stops or "inhibits" their treatment product from working, which makes it harder to stop or prevent a bleeding episode.

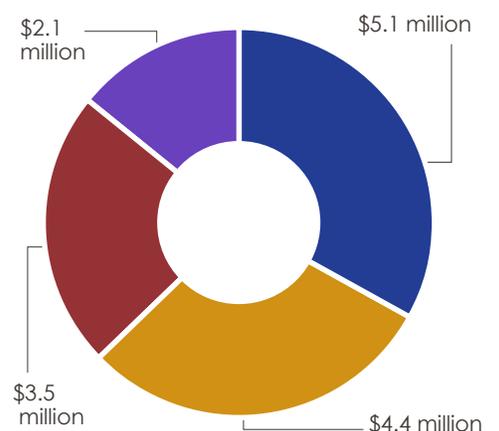
Thalassemia – Thalassemia is a group of genetic red blood cell disorders that cause an anemia beginning at birth and lasting throughout life. As a result of extensive outreach during the past 3 years, enrollment in the thalassemia patient database has increased 27%, reaching 1,014 people diagnosed with this rare disorder.



PROTECTING PEOPLE AND PREVENTING COMPLICATIONS OF BLOOD DISORDERS

Funding Chart of Blood Disorders Investment

Total \$15.1M



- Hemophilia Treatment Centers
- Public Health Approach to Blood Disorders
- Hemophilia
- Thalassemia



2017 Successes

Better You Know

NCBDDD partnered with the National Hemophilia Foundation to launch “Better You Know,” a public health education campaign to increase awareness about the signs, symptoms, and diagnoses 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 tools to help women determine their risk for a bleeding disorder and next steps to seek care.

Second Inhibitor Summit

In 2017, CDC convened the Second Inhibitor Summit to discuss how inhibitors are monitored and how a tracking system could be better

used or improved to prevent inhibitors among hemophilia patients. Prominent leaders in the bleeding disorders community attended the meeting, including care providers, researchers, patient advocacy partners, federal partners, and representatives of pharmaceutical companies.

Alpha Thalassemia Webinar

CDC worked with the Association Public Health Laboratories' Hemoglobinopathy Work Group to conduct a two-part webinar on Alpha Thalassemia. The series described the different types of Alpha Thalassemias, the importance of reporting the diagnosis and treatment of Alpha Thalassemia, and the current status of Alpha Thalassemia screening across the United States.

Priorities for the future

- **Understanding burden:** Harness new tools to analyze electronic health records, state wide monitoring systems, and existing healthcare databases to understand the populations affected by blood clots and hemoglobinopathies.
- **Improving prevention:** Work with partners to promote better treatment and follow-up care options for people affected by blood disorders.
- **Empowering people to participate and to learn:** Create tools and awareness campaigns to teach Americans about the power they have to prevent blood disorder complications and to find the right healthcare provider.
- **Reducing health disparities:** Connect vulnerable populations affected by blood disorders with healthcare centers and support systems to ensure access to consistent and high-quality care.

1 IN 10

**PEOPLE 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