Community Counts

Health Outcomes Monitoring Program for Hemophilia

- About **20,000 males in the United States are living with hemophilia**, a condition that prevents a person's blood from clotting properly.
- Hemophilia A is about **4 times more common** than hemophilia B.
- During their lifespan, about **1 in 5 people with hemophilia** will develop an inhibitor, an antibody that prevents treatment products from clotting the blood and stopping the bleeding.
- **Blacks and Hispanics are twice** as likely as whites to develop inhibitors.
- Inhibitors can occur at any age, but **children younger than age 2 years are at greatest risk.**
- The treatment for bleeding is not as effective for people with hemophilia who have an inhibitor.
- The excess healthcare costs associated with inhibitors in the United States is **nearly $1.4 billion per year.**

Program Goal

The goal of the program is to monitor the health of, and reduce complications affecting people living with hemophilia and other bleeding disorders who are receiving care at more than 140 U.S. hemophilia treatment centers (HTCs).

Community Counts

CDC's 20+ year history of monitoring hemophilia has been improved by our current Community Counts program, where we expand the types of patients monitored, collect more detailed health information and test patient blood samples for inhibitors in addition to infections. We have collected data on **more than 15,000 unique participants in the Community Counts Registry for Bleeding Disorders Surveillance.** CDC's laboratory plays a critical role in monitoring the health of people with hemophilia and bleeding disorders by screening them for infections and inhibitors; **more than 37,000 blood samples** have been collected and tested.

Managing bleeding episodes can be challenging and expensive when patients have an inhibitor. CDC's Community Counts program monitors complications and informs best practices in hemophilia care.

Geographic Distribution of Males with Hemophilia A or B Registered Into HTCs by State of Residence, 1/2012-3/2018