

COMMUNITY COUNTS



Community Counts!

CDC Public Health Surveillance for Bleeding Disorders

Over 115 HTC's Now
Participating and Over
28,000 HTC Population
Profile Forms Submitted

To learn more, visit
www.athn.org

The Centers for Disease Control and Prevention (CDC) funded the American Thrombosis and Hemostasis Network (ATHN), a nonprofit organization committed to advancing and improving care for individuals with bleeding and clotting disorders, to lead Community Counts: The CDC Public Health Surveillance for Bleeding Disorders project on behalf of the U.S. Hemostasis and Thrombosis Center Network (HTCN).

Community Counts is made up of three projects:

- HTC Population Profile
- Mortality Reporting
- Registry for Bleeding Disorders Surveillance

The **HTC Population Profile** is taking a head count of the bleeding and clotting disorders population and asking questions to help learn more about the patients receiving care within the federally funded HTC network.

Mortality Reporting tracks the demographics, diagnoses, and causes of death of patients who received care at HTC's and have died since September 30, 2011. This will be used to look at trends in the causes of death over time among persons with bleeding disorders.

The **Registry for Bleeding Disorders Surveillance** is a collection of more detailed clinical information related to bleeding disorders and their impact on patients. Data will be used to:

- Monitor trends
- Measure rates of, and risk factors for, complications
- Identify high-risk populations for prevention programs
- Identify issues that require further study

Community Counts is open to all patients with hemophilia A and B, von Willebrand disease, rare bleeding disorders, platelet disorders, and some clotting disorders receiving care at federally funded treatment centers.

The information collected by the HTC's for Community Counts is secure and private under the HIPAA Privacy Rule. For the Registry, patients will be asked to sign an authorization or consent form. The HTC staff will then look-up information from their medical record and may ask questions about how the complications of hemophilia and other bleeding disorders affect activities like working or going to school. You may be asked to give a blood sample. Joining is that simple. Visit your HTC and ask about participating in Community Counts!

Talk with your HTC team to learn about this project or visit www.athn.org. This project is funded through CDC grant #1U27DD000862-01.

