



COMMUNITY COUNTS

Where you
can make a
difference.

Community Counts is a comprehensive project aimed at learning more about patients with bleeding and clotting disorders at hemophilia treatment centers (HTCs) nationwide. The goal is to increase knowledge of inhibitors and other complications, reduce and prevent them from happening and ultimately improve the quality of life of people with bleeding disorders.

Building a better understanding

Community Counts is made up of three key components:

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

The HTC Population Profile is taking a head count and asking questions to help learn more about the patients with bleeding disorders receiving care within the federally funded HTC network. Since 2012, more than 38,000 patients have been counted at 134 participating HTCs across the country.

Second, the Registry for Bleeding Disorders Surveillance is collecting detailed clinical information that is adding to what is known about:

- Inhibitors and other complications of bleeding disorders
- Trends in medical complications and treatment of bleeding disorders over time
- Identifying high-risk populations

Third, the Mortality Reporting component is gathering information about causes of death among people with bleeding disorders receiving care at HTCs.

“This critical information will help us all better understand the complications of these disorders and develop appropriate prevention strategies — and the more participation we get, the more we can learn.”

Vanessa R. Byams, MPH, Acting Team Lead, Bleeding Disorders Team, Epidemiology and Surveillance Branch of the CDC

How you can be part of Community Counts

Led by the American Thrombosis and Hemostasis Network (ATHN) in partnership with the U.S. Hemophilia Treatment Center Network and the Centers for Disease Control and Prevention (CDC), Community Counts is happening at HTCs nationwide. The project is open to all patients with hemophilia A and B, von Willebrand disease, rare bleeding disorders, platelet disorders and some clotting disorders who are receiving care at federally funded HTCs.*

To participate, talk to your HTC and ask to be included in Community Counts!

Your data has national significance

Another benefit of participating in Community Counts is that the data gathered locally at HTCs is also being used as a national data source for some of the Healthy People 2020 (HP2020) blood disorder-specific measures. HP2020 is the national agenda for improving health and preventing disease in the U.S. These measures are significant because they keep blood disorders at the forefront of national research, program planning and policy efforts.



Securing Data. Advancing Knowledge. Transforming Care.

*The information collected for Community Counts is secure and private under the HIPAA Privacy Rule. For the Registry component, the HTC may look up your medical records and ask questions about how the complications of hemophilia and other bleeding disorders affect everyday activities like working or going to school. You may be asked to give a blood sample.



About ATHN and Community Counts

The American Thrombosis and Hemostasis Network (ATHN) is a nonprofit organization committed to advancing and improving care for individuals affected by bleeding and clotting disorders. Community Counts is led by ATHN in partnership with the U.S. Hemophilia Treatment Center Network and the Centers for Disease Control and Prevention (CDC). The project is funded under grant #U27DD000862.

To participate in Community Counts, contact your HTC. Or, to learn more:

- Go to www.athn.org
- Search for "Community Counts" at www.cdc.gov
- Contact Becky Dudley at bdudley@athn.org



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