

HEALTHY PEOPLE 2020 MEASURES

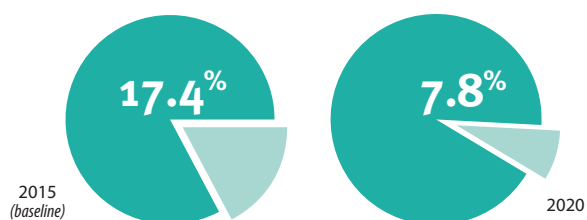
for People with Bleeding Disorders

Data on the Healthy People 2020 (HP2020) measures for people with bleeding disorders is gathered at over 135 hemophilia treatment centers (HTCs) across the country through Community Counts: CDC Public Health Surveillance Project for Bleeding Disorders. The National Hemophilia Program Coordinating Center (NHPCC), in collaboration with the Health Resources and Services Administration (HRSA), uses this data to report on bleeding disorder-specific measures as part of the HP2020 national agenda for improving health in the United States. Both Community Counts and the NHPCC are administered through the American Thrombosis and Hemostasis Network (ATHN) with federal funding. Thank you ATHN-affiliated HTCs and patients. Without your hard work and dedication we would not be able to carry out our mission.

Comprehensive Care Works!

The HP2020 measures for people with bleeding disorders data supports the HTC comprehensive care model, which coordinates all medical, psychological, social, and economic aspects of patient care to improve outcomes and quality of life.

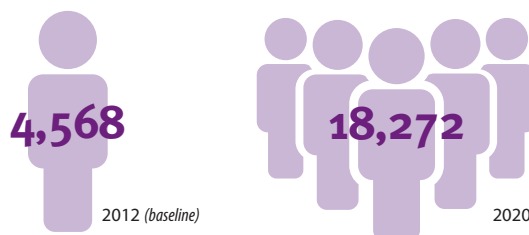
JOINT DISEASE (BDBS-16)



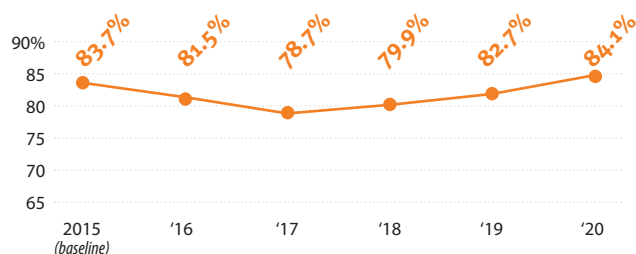
- ➔ **MEASURE** Reduce the number of persons with severe hemophilia who have >4 joint bleeds per year.
- ➔ **RESULT** Patients with severe hemophilia who have >4 joint bleeds per year decreased from 17.4% in 2015 to 7.8% in 2020.

VON WILLEBRAND DISEASE (VWD) (BDBS-15)

- ➔ **MEASURE** Increase the number of persons with VWD who are seen in specialty care centers by age 21.
- ➔ **RESULT** Between 2012-2020, the number of persons under the age of 21 with VWD receiving care at HTCs increased by an average of 1,711 per year.



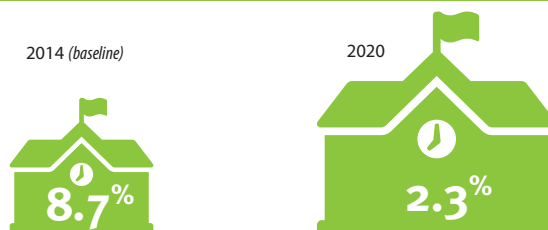
HIGH SCHOOL COMPLETION (BSBS-8)



- ➔ **MEASURE** Increase the number of persons with a diagnosis of inherited bleeding disorders who complete high school or obtain GED equivalent by age 25.
- ➔ **RESULT** The percentage of persons who completed high school or earned a GED increased by 1.4% from 2019 to 2020.

ABSENTEEISM (AH-5.6)

- ➔ **MEASURE** Decrease school absenteeism among adolescents with bleeding disorders due to illness or injury.
- ➔ **RESULT** Number of adolescents ages 12-17 who missed 11+ days due to their bleeding disorder decreased from 8.7% in 2014 to 3.8% in 2019 and further decreased to 2.3% in 2020.



DATA SOURCE Community Counts: Disorders / Community Counts Registry as of January 12, 2021

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