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The Universal Data Collection Program

Report on the Universal Data Collection Program (UDC)

Includes data collected from
May 1998 through June 2000

U. S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Centers for Disease Control and Prevention
Atlanta, Georgia 30333

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Single copies of the *Report on the Universal Data Collection Program* are available free from HANDI, the information service of the National Hemophilia Foundation by calling (800) 42-HANDI. Confidential information, referrals, and educational material on hemophilia and other bleeding disorders is also available through HANDI. The *Report on the Universal Data Collection Program* is accessible via internet at http://www.cdc.gov/ncidod/dastlr/Hematology/HDBarchive.htm.

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Commentary

The two most common congenital bleeding disorders are von Willebrand disease (vWD) and hemophilia. vWD is caused by defective synthesis or function of a protein, called von Willebrand factor, which is necessary for normal blood clotting. vWD occurs with equal frequency in men and women. Although the prevalence of this disease is not precisely known, it is estimated that between one and two percent of the population are affected. There are different types and severity of vWD. Symptoms include heavy or prolonged menstrual bleeding, easy bruising, frequent or prolonged nosebleeds, and prolonged bleeding following surgery, dental work, childbirth, or injury.

Hemophilia is caused by a defect in the gene located on the X chromosome that contains the genetic code for one of the clotting factor proteins necessary for normal blood clotting. A deficiency of factor VIII is referred to as hemophilia A or "classic" hemophilia. In contrast, a deficiency of factor IX characterizes hemophilia B, also known as Christmas disease. The defect usually occurs on one of the two female X chromosomes and results in a carrier state. When males have the defect on their only X chromosome, they are affected with the disease. Thus, almost all of the approximately 17,000 persons with hemophilia in the United States are male.

People with severe hemophilia can experience serious bleeding into tissues, muscles, joints, and internal organs, often without any obvious trauma. Repeated bleeding into joints without adequate treatment results in crippling chronic joint disease, one of the severe complications of bleeding disorders. In the mid-1970s, treatment for hemophilia was improved through the use of clotting factor concentrates, products made from the plasma of donated blood. However, because blood donations from thousands of donors are pooled together to make these products, many persons with bleeding disorders were infected with hepatitis B and C viruses and with human immunodeficiency virus (HIV), the virus that causes AIDS, before the risk of disease transmission in blood products was recognized and prevention measures taken.

In 1975, Congress initiated federal funding to specialized hemophilia treatment centers (HTCs) to provide comprehensive care to persons with bleeding disorders. Since 1986, CDC has been involved with the hemophilia community through the HTC system, primarily through risk-reduction efforts aimed at preventing secondary infection of family members with HIV.

In 1991, CDC received a request from the National Hemophilia Foundation to expand their collaborative activities within the bleeding disorders community. Meetings with patients and hemophilia care providers were held during 1992 to determine the areas of highest priority. Based on recommendations from these constituents, a Congressional mandate was issued to CDC, with the goal of reducing the human suffering and financial burden of bleeding disorders by focusing national emphasis on prevention and early intervention. The issues of greatest concern identified by the bleeding disorders community were: 1) the safety of the blood supply from infectious diseases; and 2) the prevention of joint disease.

In response, CDC developed the Universal Data Collection Program (UDC). The purpose of UDC is two-fold: 1) to establish a sensitive blood safety monitoring system among persons with bleeding disorders; and 2) to collect a uniform set of clinical outcomes information that could be used to monitor the occurrence of and potential risk factors for infectious diseases and joint complications.

Persons with bleeding disorders are enrolled in UDC by care providers in each of the nation's 134 federally funded HTCs. As part of the project, a uniform set of clinical data and plasma specimens are collected by HTC staff each year during the participant's annual

comprehensive clinic visit. A portion of the plasma specimen is used to perform free screening tests for hepatitis A, B, and C viruses and for HIV. The remainder of the specimen is stored for use as needed in future blood safety investigations.

Enrollment in UDC began in May 1998. Information about eligibility requirements, enrollment procedures, and data collection can be found in the *Technical Notes* of this report. Participating HTCs are listed by region in the *Acknowledgements*. A regional map is included at the end of this report.

The purpose of this surveillance report is to disseminate the information being collected by this project to public health workers, health educators and planners, other care providers, and patients in the bleeding disorders community. The report contains information about the demographic characteristics of the participants, their blood and factor product use, and the occurrence and treatment of joint and infectious diseases. We hope that this information will prove useful to those involved in efforts to reduce or prevent the complications of these conditions.

The proper interpretation and appropriate use of surveillance data require an understanding of how the data are collected, reported, and analyzed. Therefore, readers of this report are encouraged to review the *Technical Notes*, beginning on page 23.

Suggested Reading:

CDC. Prevention of hepatitis A through active or passive immunization. Recommendations of the Advisory Committee on Immunization Practices (ACIP). *MMWR* 1996;45(No. RR-15):1-30.

CDC. Transmission of hepatitis C virus infection associated with home infusion therapy for hemophilia. *MMWR* 1997;46:597-599.

CDC. Occurrence of hemophilia in the United States. American Journal of Hematology 1998; 59:288-294.

Hill H, Stein S. Viral infections among patients with hemophilia in the state of Georgia. American Journal of Hematology 1998;59:36-41.

The following publications are available from HANDI (800-42-HANDI):

- *What You Should Know about Bleeding Disorders* (1997)

- *Comprehensive Care for People with Hemophilia* by Shelby Dietrich, MD (1991)

- *Understanding Hepatitis* by Leonard Seeff, MD (1997)

- *HIV Disease in People with Hemophilia: Your Questions Answered* by Glenn Pierce, MD, PhD (1991)

- *Bleeding Disorders and AIDS: The Facts* (1997)

- Information packet on von Willebrand disease.

Table 1. Enrollment in UDC, May 1998 – June 2000

Month	Number Enrolled	Number Refused	Refusal Rate (%)
May – Dec 1998	1425	136	8.7
Jan – Dec 1999	3882	537	12.2
January 2000	218	41	15.8
February	234	34	12.7
March	279	55	16.5
April	238	43	15.3
May	227	61	21.2
June	267	47	15.0
Total	**6770**	**954**	**12.4**

Table 2. Regional* enrollment activity, May 1998 – June 2000

Region	Number Approached	Number Enrolled	Refusal Rate (%)
I	254	228	10.2
II	891	757	15.0
III	983	821	16.5
IV-N	603	566	6.1
IV-S	381	334	12.3
V-E	406	352	13.3
V-W	718	666	7.2
VI	723	619	14.4
VII	294	256	12.9
VIII	359	346	3.6
IX	764	700	8.4
X	36	34	5.6

*See map (page 29) for regional designations.

Table 3. Demographic characteristics of persons* enrolled in UDC

Characteristic	Hemophilia A (n = 3835) Number	Hemophilia A (n = 3835) Percent	Hemophilia B (n = 901) Number	Hemophilia B (n = 901) Percent	vWD (n = 889) Number	vWD (n = 889) Percent
Age Group (years)						
2 – 10	1087	28.4	217	24.1	237	26.7
11 – 20	1170	30.6	246	27.4	321	36.1
21 – 40	951	24.8	269	29.9	169	19.0
41 – 60	536	14.0	129	14.3	121	13.6
61+	84	2.2	38	4.2	41	4.6
Race / Ethnicity						
White	2636	68.7	664	73.7	655	73.7
African American	476	12.4	104	11.5	44	4.9
Hispanic	484	12.6	95	10.5	83	9.3
Asian / Pacific Islander	91	2.4	14	1.6	27	3.0
Native American	33	0.9	6	0.7	7	0.8
Other	115	3.0	18	2.0	73	8.2
Sex						
Male	3769	98.3	875	97.1	424	47.7
Female	65	1.7	26	2.9	465	52.3

*32 persons were reported to have both hemophilia and vWD, and 119 persons had a bleeding disorder other than hemophilia or vWD.

Figure 1. Age at diagnosis for persons with hemophilia enrolled in UDC, by hemophilia severity

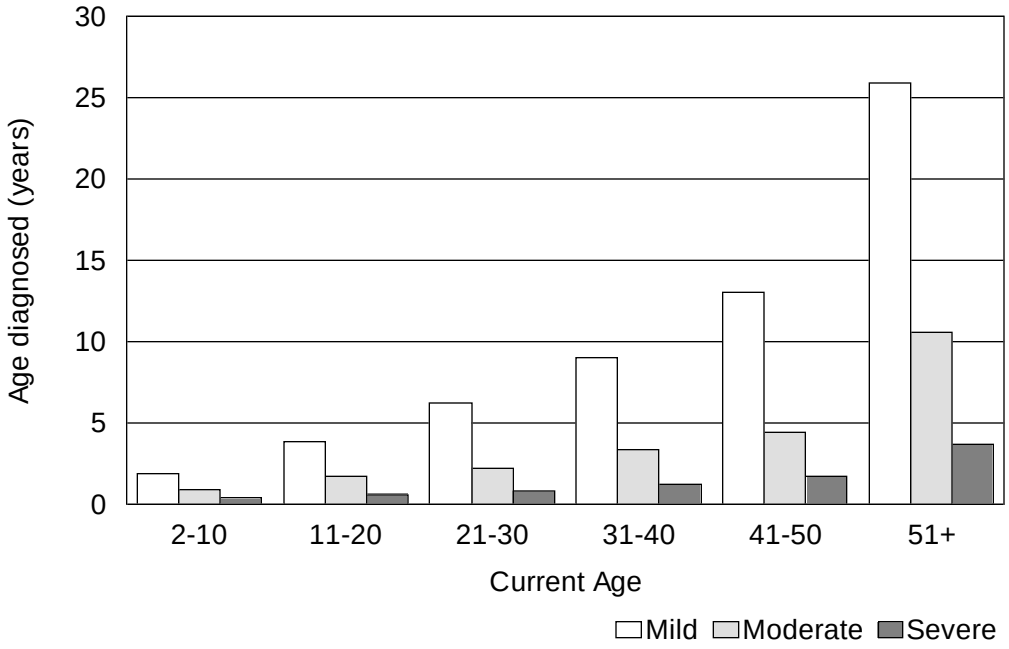

Figure 2. Age at diagnosis for persons with vWD enrolled in UDC, by vWD type

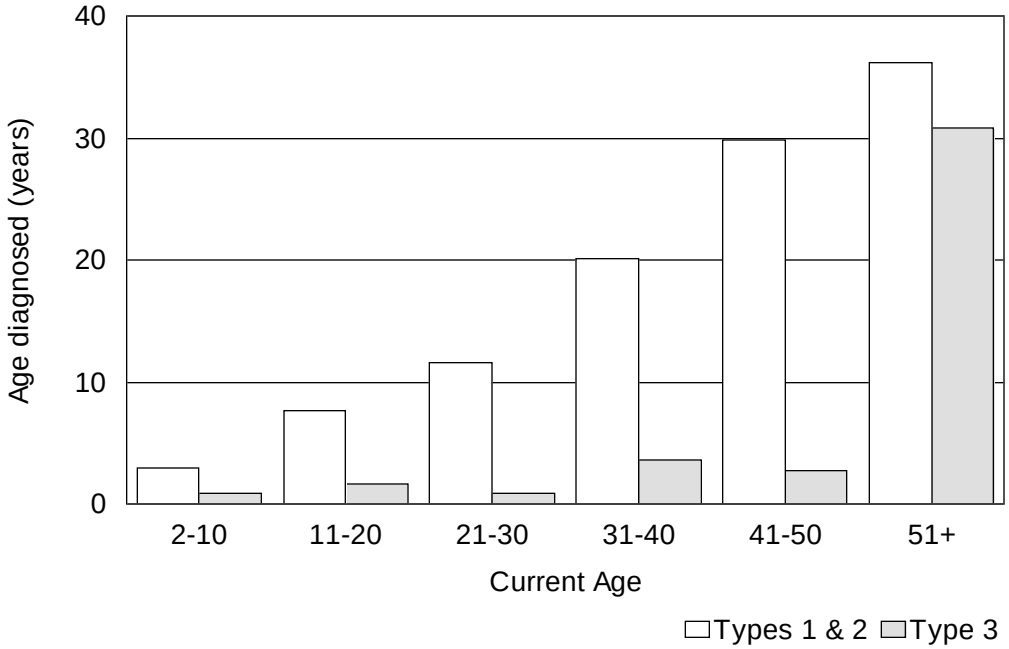

Table 4. Sources* of health care reimbursement listed by persons enrolled in UDC

Reimbursement Source	Hemophilia (n=4736) Number	Hemophilia (n=4736) % of Total	vWD (n=856) Number	vWD (n=856) % of Total
Straight Commercial	1111	23.4	231	27.0
Commercial Insurance HMO	921	19.4	191	22.3
Commercial Insurance PPO	667	14.0	133	15.5
Straight Medicare	408	8.6	48	5.6
Medicare HMO	37	0.8	6	0.7
Straight Medicaid	1015	21.4	120	14.0
Medicaid HMO	263	5.5	63	7.4
CHAMPUS	30	0.6	13	1.5
State High Risk Plan	99	2.1	6	0.7
Other	623	13.1	150	17.5
Uninsured	200	4.2	25	2.9

*Some persons may have listed more than one source of reimbursement.

HMO = Health maintenance organization; PPO = Preferred provider organization

Table 5. Bleeding disorder severity among persons enrolled in UDC

	Hemophilia						vWD			
	Mild		Moderate		Severe		Type 1 & 2		Type 3	
	N	%	N	%	N	%	N	%	N	%
Participants*	1009	21.3	1078	22.8	2639	55.8	715	88.4	94	11.6

*Numbers do not equal total number of persons because of missing data.

Table 6. Bleeding episodes* among persons enrolled in UDC by bleeding disorder severity and prophylaxis status

No prophylaxis

	Hemophilia			vWD	
Bleeding site	Mild n = 1004	Moderate n = 967	Severe n = 1964	Type 1 & 2 n = 688	Type 3 n = 93
Joint	0.5 (2.1)	3.6 (7.5)	9.1 (11.9)	0.2 (1.4)	3.4 (7.7)
Muscle	0.3 (1.0)	1.0 (2.3)	2.6 (5.8)	0.3 (3.9)	0.6 (1.5)
Other	0.8 (4.1)	1.4 (4.2)	2.1 (5.3)	3.4 (11.0)	3.8 (6.5)
All sites					
Mean	1.6 (4.9)	6.0 (9.9)	13.7 (15.8)	3.9 (11.9)	7.7 (10.2)
Median	0	3	10	0	4

With prophylaxis

	Hemophilia		
Bleeding site	Mild N = 5	Moderate n = 111	Severe n = 674
Joint	1.0 (1.4)	2.7 (3.8)	3.1 (5.8)
Muscle	1.6 (3.6)	1.0 (5.0)	0.8 (2.0)
Other	1.0 (1.4)	1.1 (3.0)	1.4 (5.9)
All sites			
Mean	3.6 (4.3)	4.9 (8.7)	5.2 (9.2)
Median	2	3	2

*Values are mean (±SD) number of bleeding episodes experienced during the 6-month period preceding the UDC visit.

Figure 3. Age at first bleed for persons with hemophilia enrolled in UDC, by hemophilia severity

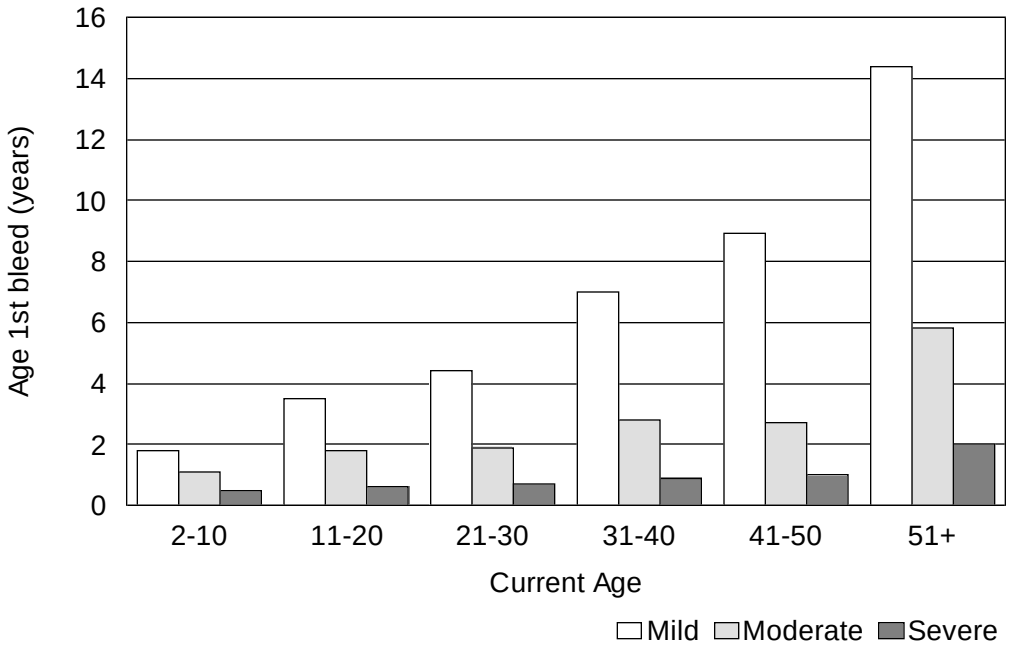

Figure 4. Age at first bleed for persons with vWD enrolled in UDC, by vWD type

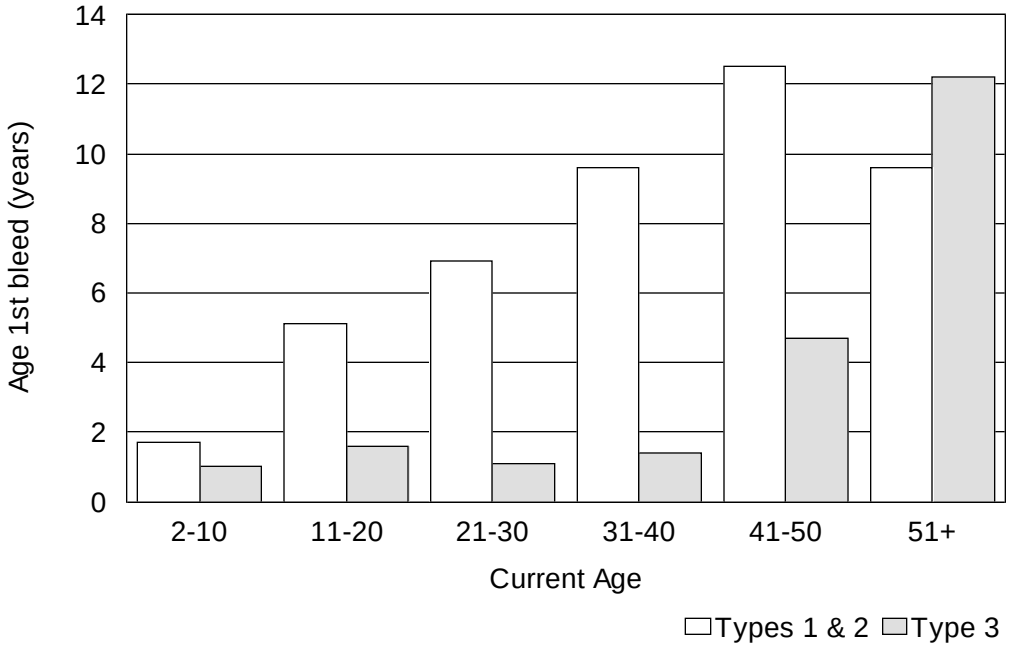

Table 7. Infectious disease complications among persons enrolled in UDC

Infectious Disease Complications	Hemophilia		vWD	
	Number	% of Total	Number	% of Total
Risk factors for liver disease				
Past/present hepatitis B virus infection	951	20.1	31	3.5
Past/present hepatitis C virus infection	2183	46.1	73	8.2
History of alcohol abuse	178	3.8	4	0.5
Other	52	1.1	13	1.5
None	2433	51.4	793	89.3
Signs or symptoms of liver disease (During the last year)				
Jaundice	30	0.6	1	0.1
Ascites	28	0.6	1	0.1
Varices	21	0.4	0	—
Other	56	1.2	1	0.1
None	4629	97.7	885	99.7
Laboratory markers of liver disease				
Chronically elevated ALT/AST levels	847	17.9	23	2.6
Elevated prothrombin time in the last year	112	2.4	12	1.4
Therapy for chronic viral hepatitis				
Any therapy	199	4.2	8	0.9
Successful therapy	34	17.1*	1	12.5*
Intravenous access devices (IVAD)				
Used an IVAD in the last year	574	12.1	27	3.0
IVAD infection in the last year	73	12.7**	3	11.1**

*Percent of persons who received any therapy for chronic viral hepatitis.
**Percent of persons who used an IVAD in the last year.

Table 8. Treatment type for persons with hemophilia enrolled in UDC

Severity	Total number	Episodic care No. (%)	Number on intermittent prophylaxis	Number on continuous* prophylaxis
Mild	1009	993 (98.4)	11	5
Moderate	1078	923 (85.6)	44	111
Severe	2639	1759 (66.6)	206	674

*Prophylaxis is considered continuous when administered for at least 46 weeks per year.

Table 9. Prevalence of current inhibitors by titer* among persons with hemophilia enrolled in UDC

	Hemophilia A			Hemophilia B		
Severity	Number	Low titer	High titer	Number	Low titer	High titer
Mild	797	4 (0.5)	1 (0.1)	212	0	0
Moderate	775	12 (1.6)	12 (1.6)	303	1 (0.3)	1 (0.3)
Severe	2254	82 (3.6)	137 (6.1)	385	5 (1.3)	15 (3.9)

*Low titer is defined as an inhibitor level of 0.5 – 5 Bethesda units (BU).
High titer is defined as an inhibitor level of >5 BU.
Numbers in parentheses are percents.

Figure 5. Age at first HTC visit for persons with hemophilia enrolled in UDC, by hemophilia severity

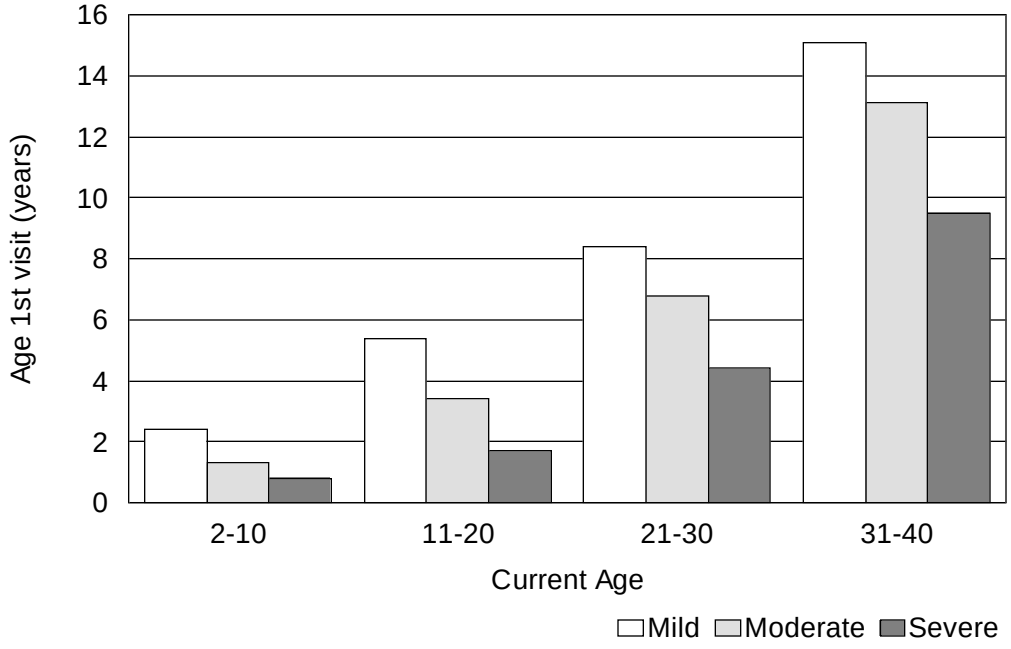

Figure 6. Age at first HTC visit for persons with vWD enrolled in UDC, by vWD type

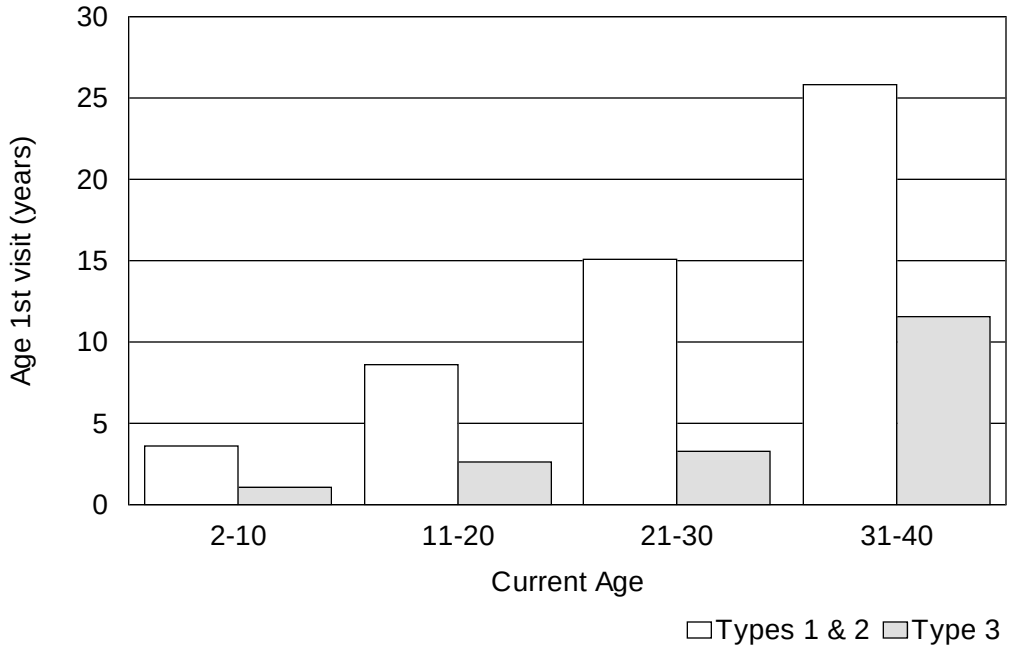

Figure 7. Prevalence of hepatitis A virus exposure and reported vaccination status among persons with hemophilia enrolled in UDC

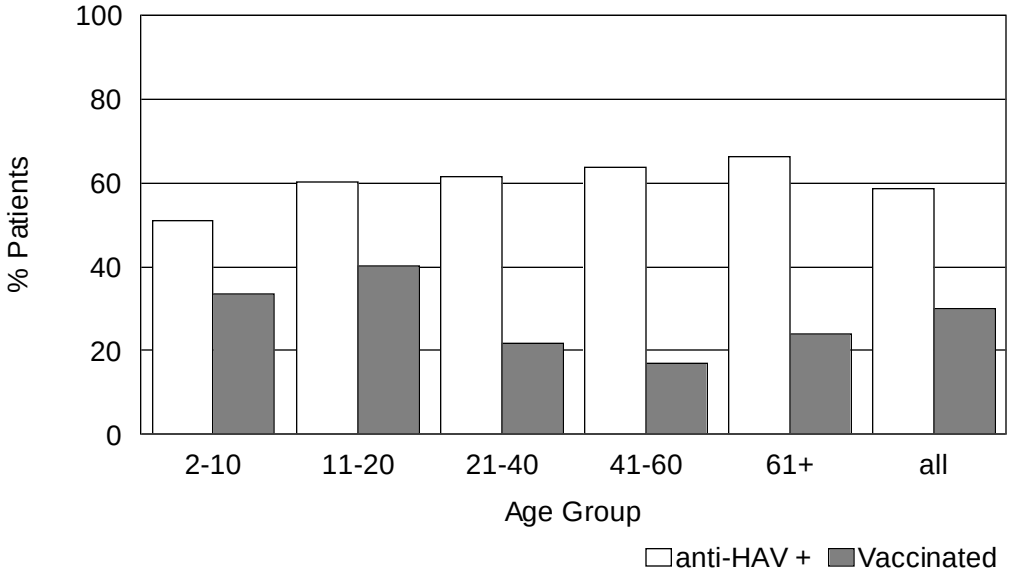

Figure 8. Regional distribution of natural and acquired immunity to hepatitis A virus among persons with hemophilia enrolled in UDC

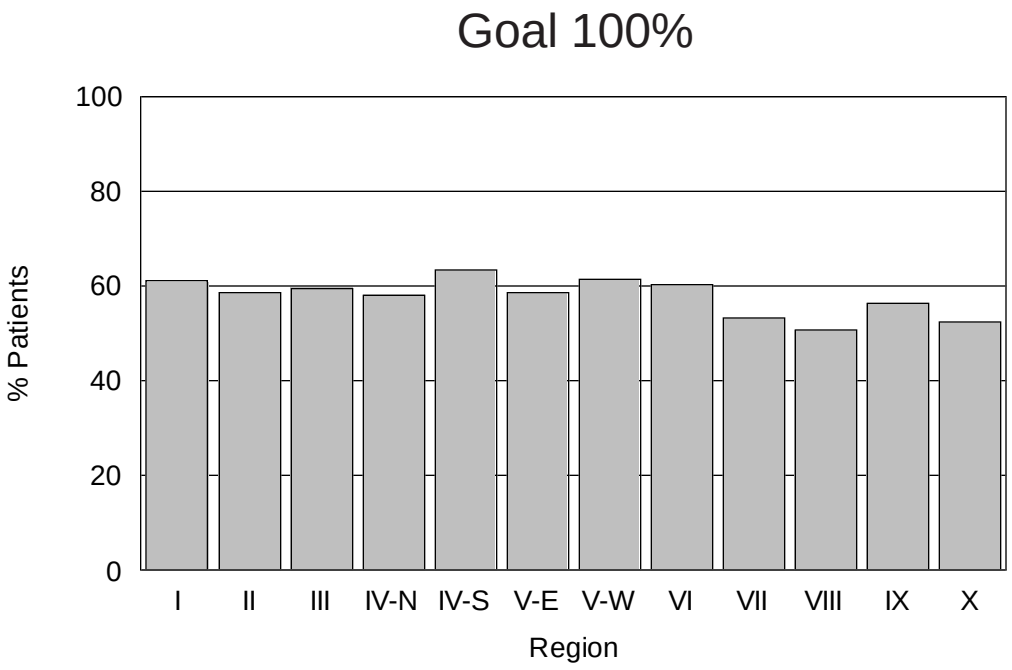

Figure 9. Prevalence of hepatitis A virus exposure and reported vaccination status among persons with vWD enrolled in UDC

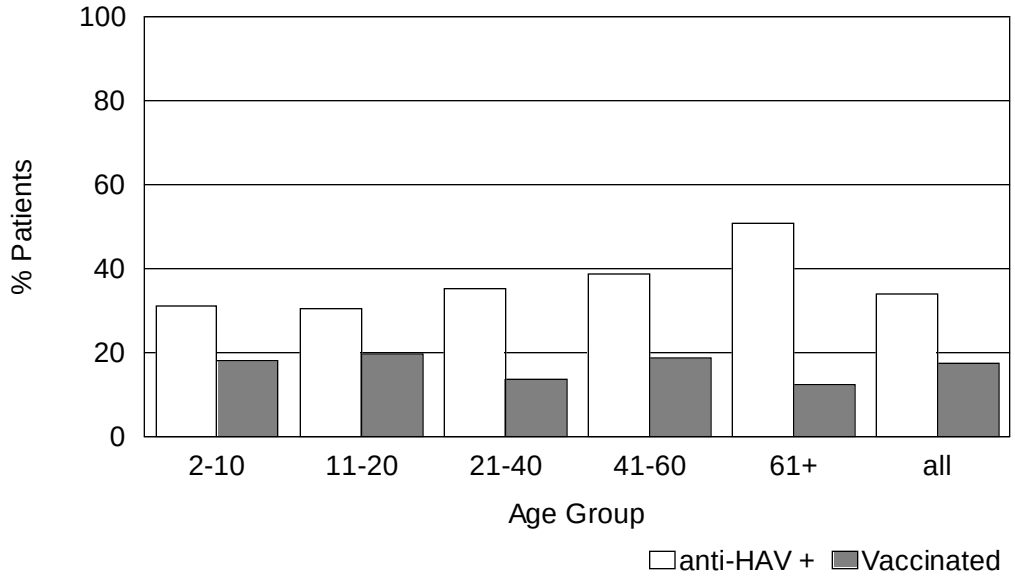

Figure 10. Prevalence of hepatitis B virus exposure and reported vaccination status among persons with hemophilia enrolled in UDC

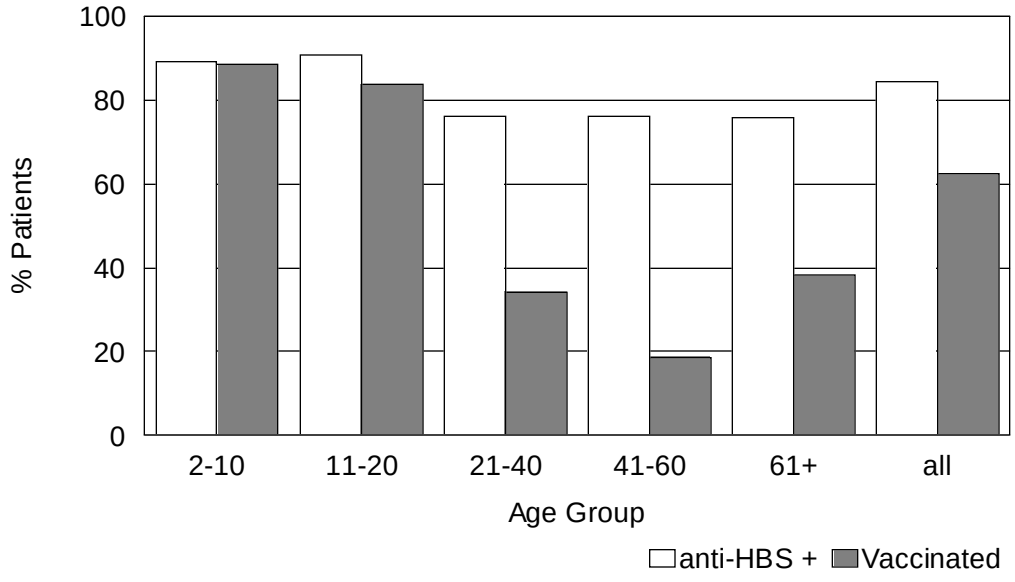

Figure 11. Regional distribution of natural and acquired immunity to hepatitis B virus among persons with hemophilia enrolled in UDC

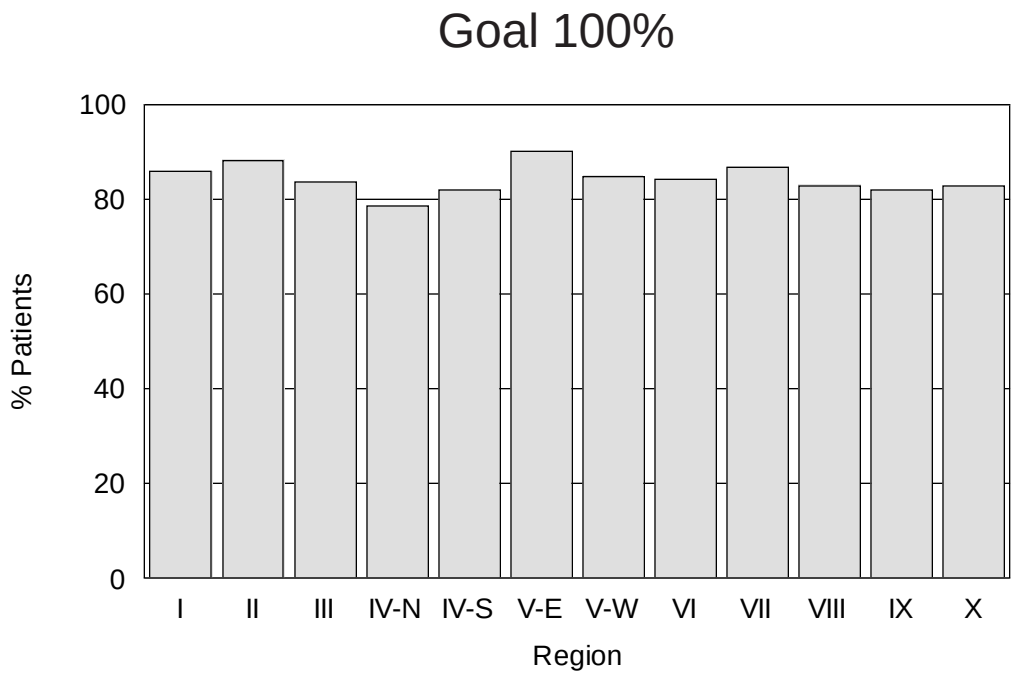

Figure 12. Prevalence of hepatitis B virus exposure and reported vaccination status among persons with vWD enrolled in UDC

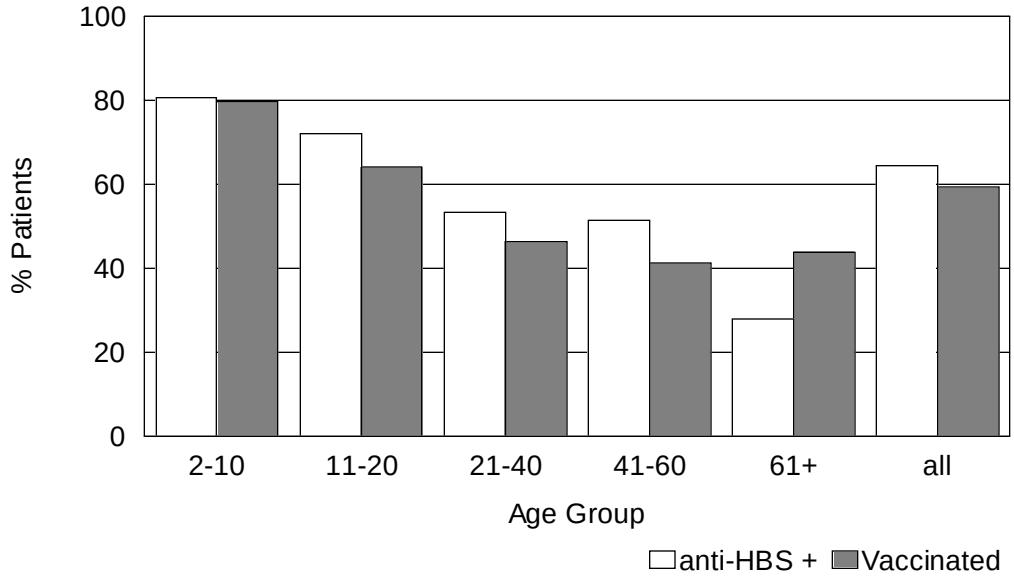

Figure 13. Prevalence of hepatitis C virus infection among persons with bleeding disorders enrolled in UDC

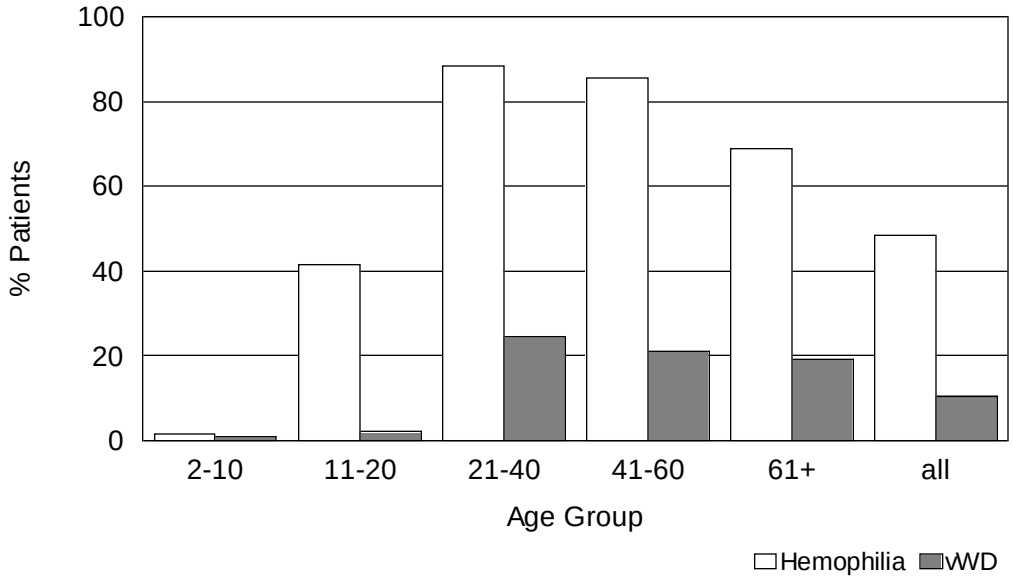

Figure 14. Prevalence of human immunodeficiency virus (HIV) infection among persons with bleeding disorders enrolled in UDC

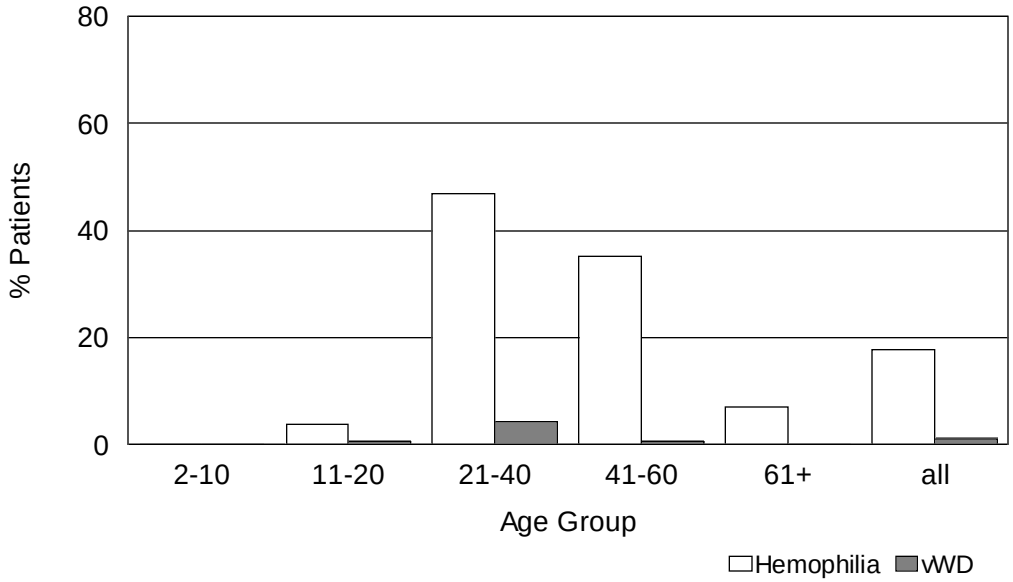

Table 10. Blood and factor products used* by persons enrolled in UDC

Treatment product	Hemophilia A		Hemophilia B		vWD	
	Number	Percent	Number	Percent	Number	Percent
Recombinant factor	2349	61.3	494	54.8	5	0.6
Monoclonal factor VIII	771	20.1	1	0.1	2	0.2
Other human factor VIII	175	4.6	1	0.1	184	21.5
Porcine factor VIII	7	0.2	0	—	0	—
Purified factor IX	2	0.1	306	34.0	1	0.1
Prothrombin complex	62	1.6	34	3.8	0	—
Activated prothrombin complex	180	4.7	11	1.2	0	—
Cryoprecipitate or FFP	16	0.4	9	1.0	17	2.0
Desmopressin	253	6.6	3	0.3	325	37.9
None used	355	9.3	150	16.6	318	37.1

*Any use of the product(s) during the 12-month period preceding the UDC visit.

NOTE: Individuals may have used more than one type of treatment product.

Table 11. Incident cases of intra-cranial hemorrhage (ICH)* among persons with hemophilia enrolled in UDC

Severity	Hemophilia A		Hemophilia B	
	Total	No. with ICH (%)	Total	No. with ICH (%)
Mild	797	2 (0.2)	212	0
Moderate	775	7 (0.9)	303	1 (0.3)
Severe	2254	24 (1.1)	385	4 (1.0)

Causes of ICH	Number (%)
Trauma	18 (54.5)
Thrombocytopenia	1 (3.0)
Other	14 (42.4)

*Diagnosed by a physician during the year prior to the UDC visit.

Table 12. Lifetime prevalence of intra-cranial hemorrhage (ICH)* among persons with hemophilia enrolled in UDC

Severity	Hemophilia A % with ICH	Hemophilia B % with ICH
Mild	5.2	6.4
Moderate	11.9	8.6
Severe	14.6	16.2

*History of ICH anytime in the person's life.

Table 13. Joint complications among persons enrolled in UDC

	Hemophilia						vWD			
	Mild		Moderate		Severe		Type 1 & 2		Type 3	
	N	%	N	%	N	%	N	%	N	%
Target joint*	81	8.0	317	29.4	1285	48.7	15	2.2	19	20.2
Invasive procedure	37	3.7	69	6.4	324	12.3	16	2.3	7	7.4
Joint infection	7	0.7	16	1.5	42	1.6	5	0.7	0	—
Used cane	130	12.9	265	24.6	827	31.3	41	5.9	20	21.3
Used wheelchair	19	1.9	63	5.8	267	10.1	18	2.6	6	6.4
Any activity restriction	141	14.0	318	29.5	1114	42.2	51	7.4	29	30.8

*Please see Technical Notes (page 23) for the definition of a target joint

Table 14. Joint limitations among persons enrolled in UDC

	Hemophilia			vWD	
	Mild	Moderate	Severe	Type 1 & 2	Type 3
Number of patients	951	990	2328	651	88
Mean indicator* value	52.3	91.9	156.8	24.8	69.4
Standard deviation	98.9	169.9	218.9	84.5	117.7

*Indicator is the total number of degrees of range of motion less than normal for five joints. The joint motions measured and normal values used (in parentheses) are: hip extension (30); hip flexion (120); knee flexion (135); knee extension (0); shoulder flexion (180); elbow flexion (150); elbow extension (0); elbow pronation and supination (80); ankle dorsiflexion (20); ankle plantar flexion (50). Any hyperextension of the knee or elbow is included in the calculation. In UDC, limitations in knee and elbow extension are recorded as negative numbers. Patients with missing measures for any of the joints are excluded from the analyses. As an example, patients with mild hemophilia have on average 52.3 degrees less than normal range of motion across ten joints. Because the sum of all of the normal measures is 1,690 degrees, this represents an overall 3.1% loss in range of motion.

Table 15. Prevalence of a positive family history of bleeding disorder among persons with hemophilia or vWD enrolled in UDC

Severity	Hemophilia A % with family history	Hemophilia B % with family history	vWD* % with family history
Mild	80.1	77.8	67.6
Moderate	72.3	81.1	
Severe	58.9	61.3	55.8

*Types 1 and 2 vWD are included in the mild category and type 3 vWD in the severe category.

Table 16. Prevalence of another person with a bleeding disorder living in the same household among persons with hemophilia or vWD enrolled in UDC

Severity	Hemophilia A % with affected household member	Hemophilia B % with affected household member	vWD* % with affected household member
Mild	29.5	27.8	47.9
Moderate	24.5	31.8	
Severe	21.0	16.6	43.4

*Types 1 and 2 vWD are included in the mild category and type 3 vWD in the severe category.

Table 17. Prevalence of having had an analysis of genetic mutation performed among persons with hemophilia enrolled in UDC

Severity	Hemophilia A % with genetic analysis	Hemophilia B % with genetic analysis
Mild	4.5	14.7
Moderate	7.0	9.6
Severe	14.9	21.7

Technical Notes

Eligibility Requirements

To participate in UDC, patients must receive care in a federally funded HTC and meet at least one of the following criteria: 1) age 2 years or older with a bleeding disorder due to congenital deficiency or acquired inhibitors in which any of the coagulation proteins is missing, reduced, or defective and has a functional level of less than 50 percent; or 2) age 2 years or older with a diagnosis by a physician of von Willebrand disease. Individuals specifically excluded from participation in UDC include persons with any of the following: 1) an exclusive diagnosis of a platelet disorder; 2) thrombophilia; or 3) coagulation protein deficiencies due to liver failure.

Data collection

UDC data are collected during the participant's "annual visit," which ideally should occur once each calendar year (January-December), with the interval between visits as close as possible to 12 months. Data are collected according to guidelines and definitions detailed in surveillance manuals provided to HTC staff by CDC. Informed consent for participation is obtained each year. Demographic information and reasons for refusal are obtained using a Patient Refusal Form for all eligible persons who decline participation. To protect patient confidentiality, all data sent to CDC do not contain personally identifying information, but rather use a unique 12-digit code that is generated by a computer software program supplied to HTCs by CDC.

Eligible participants are registered into UDC through a Registration Form completed by HTC staff; this form includes patient demographic, diagnostic, and historical information. Month and year of birth are used to calculate age on the last day of the current year. Information on race and ethnicity is obtained from clinic records and may have been based either on self-report or on observations made by care providers.

During the annual visit, clinical information is recorded on a standardized data collection form (Annual Visit Form). In addition to information about education, employment status, and health insurance, data are also collected about treatment type (episodic vs. prophylactic), presence and treatment of inhibitors, the number of bleeding episodes experienced (based on infusion logs or patient recall), type and brand name of all factor concentrates or other treatment products used, and whether or not clotting factor is infused at home.

Information regarding infectious diseases is also collected including risk factors and clinical signs, symptoms, and laboratory markers of liver disease. Data are also recorded about any therapy for chronic hepatitis, the status of vaccination for hepatitis A and B viruses, and, among patients with an intravenous access device, the occurrence of a device-associated infection. Persons $\geq$16 years of age who are HIV-infected are asked several questions concerning risk-reduction activities including partner testing and condom use.

Data are also collected on joint disease, including the use of walking aids, the occurrence of joint infections, and measures of impact of joint disease on daily activities. During the visit, range of motion measurements on five joints (hip, knee, shoulder, elbow, and ankle) are taken by a physical therapist or other trained health care provider according to detailed guidelines provided in a reference manual supplied by CDC. All health care providers performing these measurements are trained and certified by regional physical therapists who have themselves received centralized training. In addition, information about whether a particular joint is a "target joint" or whether the participant has required the use of an orthopedic appliance or has undergone an invasive orthopedic procedure is collected. In UDC, a target joint is defined as a joint in

which recurrent bleeding has occurred on four or more occasions during the previous 6 months or one in which 20 life-time bleeding episodes have occurred.

All data collection forms are sent overnight to CDC where they are then key entered into a computer database using double-entry software to minimize data entry errors. Data are then screened for omissions, inconsistencies, and unusual values that possibly represent abstraction or data-entry errors. Error reports are generated and faxed to the HTC, where a designated UDC contact uses available information to resolve discrepancies and complete missing data items.

Laboratory testing

During the annual visit, a blood specimen is obtained from each participant in UDC. The specimen is processed by HTC personnel according to guidelines provided by CDC that are designed to minimize the effects of storage and shipment on subsequent analyses. Samples are shipped overnight to the CDC Serum Bank where they are aliquoted and stored. A portion of the specimen is sent to the Eugene B. Casey Hepatitis Laboratory at Baylor College of Medicine in Houston, Texas. A second portion is sent to the HIV Testing Laboratory at CDC. The remainder of the specimen is stored in the CDC Serum Bank for future blood safety investigations, as needed.

Testing for hepatitis A, B, and C viruses follow algorithms designed to determine with the highest probability the patient's status with regard to exposure to or infection with these viruses. Information provided by HTC staff on a Laboratory Form, including the results of previous local testing and vaccination history, is used by personnel at the testing laboratory to provide a detailed interpretation of the test results.

Testing for HIV follows algorithms designed to determine patient status with regard to infection with HIV-1 and HIV-2. The results of all laboratory testing are reported to the HTC using the CDC unique code which can be matched to the patient only by HTC staff.

Mortality reporting

Deaths occurring among all HTC patients (regardless of whether or not they have been enrolled in UDC) are reported to CDC using a Mortality Form. Data collected include age at death, sex, race/ethnicity, disease type and severity, and whether or not blood products had been used during the year prior to death. Additionally, information about the death, including the date, cause (primary and contributing), and whether or not an autopsy was performed, is also collected.

Tabulation and presentation of data

Data in this report are provisional. The data presented in this report represent the first 22 months of what is planned to be at least a 5-year surveillance project. Future reports will include expanded data tables to cover subsequent surveillance periods and will provide the results of more detailed analyses of available data and findings from special studies.

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Lebanon, NH
Rhode Island Hospital
Providence, RI
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Adult, Buffalo, NY
Hemophilia Center of Western New York –
Pediatric, Buffalo, NY
Albany Medical College
Albany, NY
UHSH Blood Disorders Center
Johnson City, NY
The Mount Sinai – NYU Medical Center /
Health System, New York, NY
Long Island Jewish Medical Center
New Hyde Park, NY
The New York Presbyterian Hospital
New York, NY
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Washington, DC
University of Virginia Hospital
Charlottesville, VA
Medical College of Virginia Hospital
Richmond, VA
Children's Hospital of the King's Daughters
Norfolk, VA
Cardeza Foundation Hemophilia Center
Philadelphia, PA
Christiana Care Health Services
Newark, DE
Hemophilia Center of Central Pennsylvania
Hershey, PA
Hemophilia Center of Western Pennsylvania
Pittsburgh, PA
West Virginia University Medical Center
Morgantown, WV
Charleston Area Medical Center
Charleston, WV
Johns Hopkins University Medical Center
Baltimore, MD
Children's Hospital of Philadelphia Speciality
Center, Voorhees, NJ
Children's Hospital of Philadelphia
Philadelphia, PA
Lehigh Valley Hospital
Allentown, PA

St. Agnes Hospital
Baltimore, MD
Penn Comprehensive Hemophilia Program
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Mayo Clinic
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MeritCare Hospital DBA Roger Maris
Cancer Center, Fargo, ND
Hemophilia Outreach Centre
Green Bay, WI
Gunderson Clinic
LaCrosse, WI
American Red Cross - Badger Chapter
Madison, WI
Rush Children's Hospital
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Orthopaedic Hospital of Los Angeles
Los Angeles, CA
Children's Hospital, San Diego
San Diego, CA
Children's Hospital of Orange County
Orange, CA
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City of Hope National Medical Center
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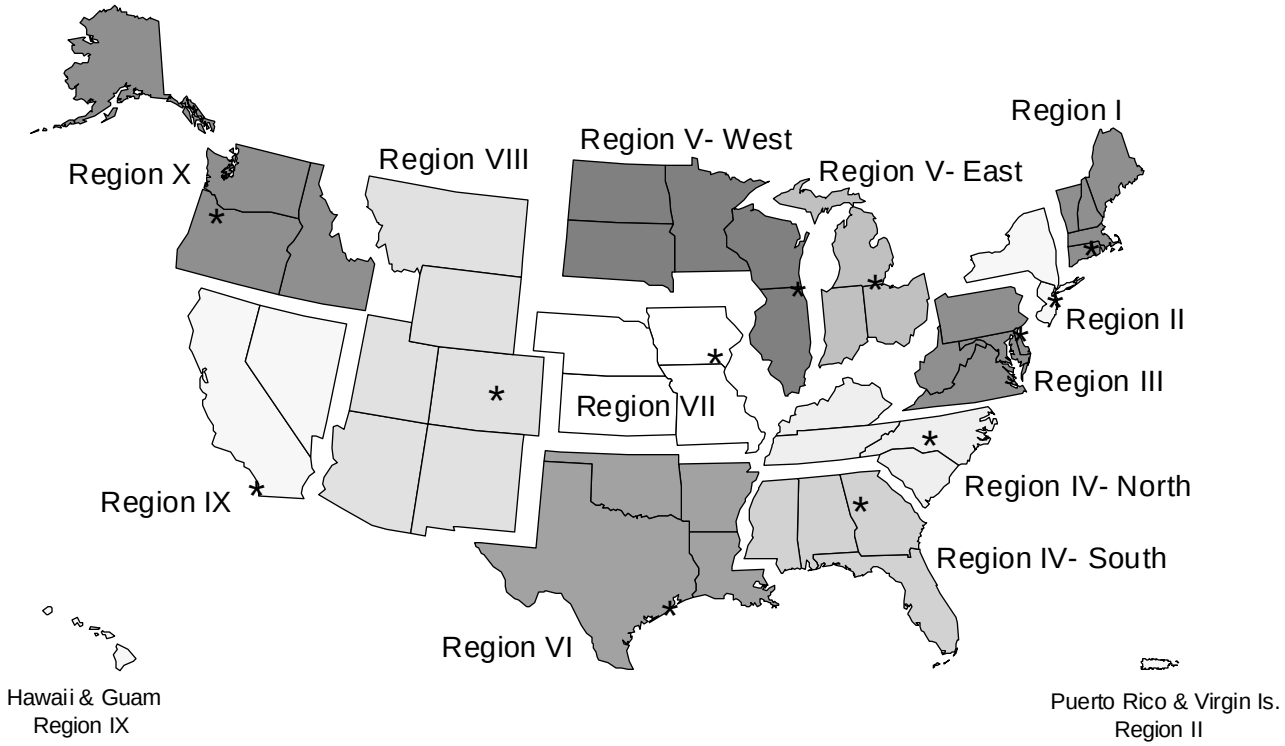
Hemophilia Treatment Center Regions



*Denotes location of regional core centers.