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UDC

The Universal Data Collection Program

Report on the Universal Data Collection Program (UDC)

Includes data collected from
May 1998 through May 2002

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

The *Report on the Universal Data Collection Program* is published by the Hematologic Diseases Branch, Division of AIDS, STD, and TB Laboratory Research, National Center for Infectious Diseases, Centers for Disease Control and Prevention (CDC), Atlanta, Georgia 30333. All data are provisional.

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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/HDBpubs.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 concen-trates, 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 22.

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 by date, May 1998 – May 2002

Month(s)	Number Approached	Number Enrolled	Number Refused (%)
Pilot period	41	39	2 (4.9)
May – Dec 1998	1564	1428	136 (8.7)
Jan – Dec 1999	4453	3910	543 (12.2)
Jan – Dec 2000	3388	2847	541 (16.0)
Jan – Dec 2001	2417	1902	515 (21.3)
January 2002	207	162	45 (21.7)
February 2002	213	183	30 (14.1)
March 2002	209	173	36 (17.2)
April 2002	199	161	38 (19.1)
May 2002	170	140	30 (17.6)
Total	**12861**	**10945**	**1916 (14.9)**

Table 2. Enrollment in UDC by region,* May 1998 – May 2002

Region	Number Approached	Number Enrolled	Number Refused (%)
I	540	439	101 (18.7)
II	1468	1196	272 (18.5)
III	1719	1359	360 (20.9)
IV-N	1084	995	89 (8.2)
IV-S	884	779	105 (11.9)
V-E	1384	1165	219 (15.8)
V-W	1207	1070	137 (11.4)
VI	1271	1058	213 (16.8)
VII	693	582	111 (16.0)
VIII	628	595	33 (5.3)
IX	1480	1300	180 (12.2)
X	396	308	88 (22.2)
Total	**12861**	**10945**	**1916 (14.9)**

*See map (page 28) for regional designations.

Figure 1. Number of years follow-up for persons enrolled in UDC

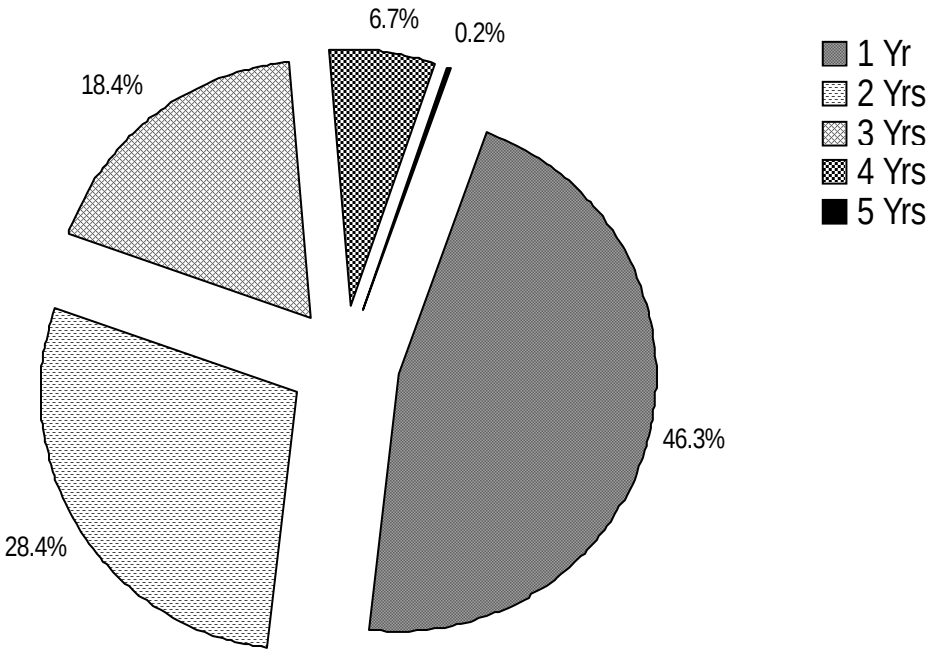

Figure 2. Visits by UDC participants through May 2002

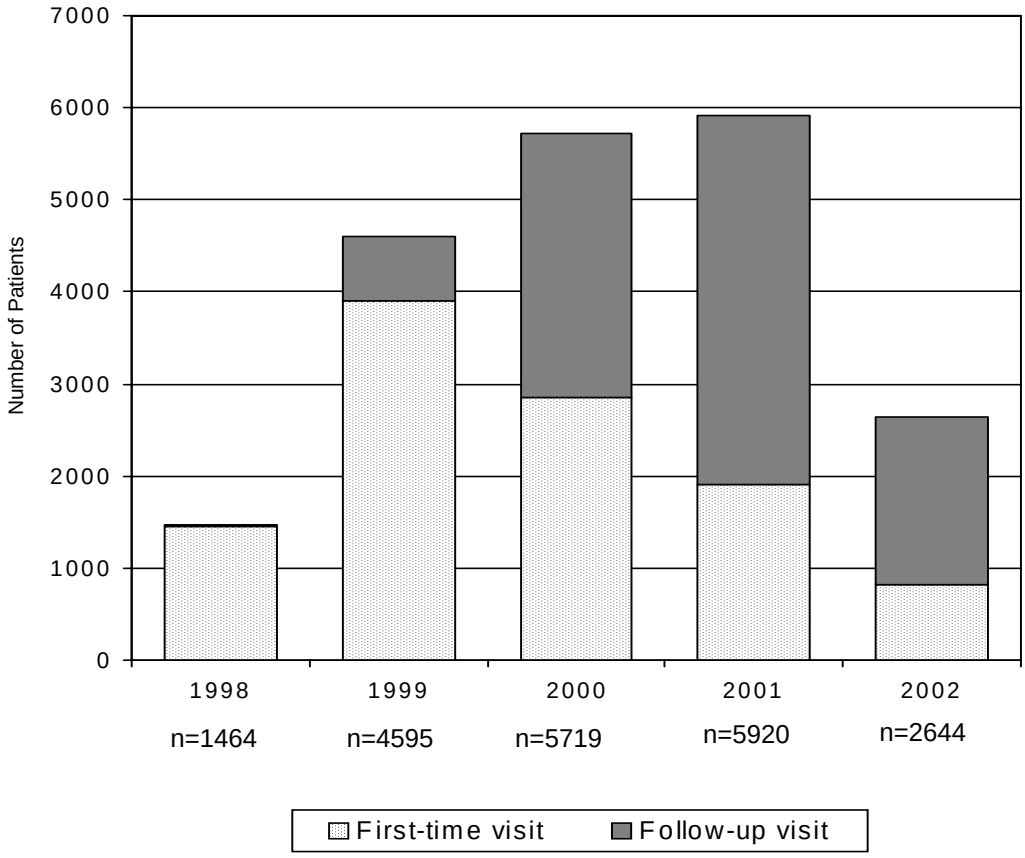

Table 3. Demographic characteristics of persons* enrolled in UDC

	Hemophilia				vWD	
	A (n = 6824)		B (n =1826)		(n = 2051)	
Characteristic	Number	Percent	Number	Percent	Number	Percent
Age Group						
2 – 10	1574	23.1	404	22.1	406	19.8
11 – 20	2240	32.8	531	29.1	791	38.6
21 – 40	1814	26.6	485	26.6	430	21.0
41 – 60	990	14.5	316	17.3	316	15.4
61+	206	3.0	90	4.9	108	5.3
Race / Ethnicity						
White	4714	69.1	1366	74.8	1559	76.0
African American	854	12.5	204	11.2	112	5.5
Hispanic	854	12.5	177	9.7	197	9.6
Asian / Pacific Islander	177	2.6	27	1.5	59	2.9
Native American	50	0.7	14	0.8	16	0.8
Other	175	2.6	38	2.1	108	5.3
Sex						
Male	6695	98.1	1767	96.8	894	43.6
Female	129	1.9	59	3.2	1157	56.4

*Forty-nine persons were reported to have both hemophilia and vWD (these persons are included in analyses as hemophilia patients only and not vWD patients). A total of 234 persons had a bleeding disorder other than hemophilia or vWD.

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

	Hemophilia (n=8650)		vWD (n=2051)	
Reimbursement Source	Number	% of Total	Number	% of Total
Straight Commercial	1752	20.3	510	24.9
Commercial Insurance HMO	1628	18.8	480	23.4
Commercial Insurance PPO	1599	18.5	398	19.4
Straight Medicare	729	8.4	117	5.7
Medicare HMO	75	0.9	22	1.1
Straight Medicaid	1783	20.6	240	11.7
Medicaid HMO	481	5.6	149	7.3
CHAMPUS	59	0.7	25	1.2
State High Risk Plan	210	2.4	20	1.0
Other	1242	14.4	324	15.8
Uninsured	343	4.0	67	3.3

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

HMO = Health maintenance organization; PPO = Preferred provider organization

Table 5. Disease severity of persons enrolled in UDC

	Hemophilia n=8650			vWD* n=1880		
	Mild n (%)	Moderate n (%)	Severe n (%)	Type 1 n %)	Type 2 n(%)	Type 3 n(%)
Participants	2081 (24.1)	1981 (22.9)	4588 (53.0)	1455 (69.3)	239 (11.4)	186 (8.9)

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

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

No prophylaxis

	Hemophilia			vWD		
	Mild	Moderate	Severe	Type 1	Type 2	Type 3
Bleeding site	n = 2070	n = 1787	n = 3271	n = 1412	n = 234	n = 183
Joint	0.6 (2.4)	3.1 (6.6)	8.8 (12.3)	0.2 (1.2)	0.2 (1.6)	1.9 (4.9)
Muscle	0.3 (1.2)	0.9 (2.2)	2.1 (5.0)	0.1 (1.4)	0.1 (0.3)	0.5 (1.4)
Other	0.8 (3.1)	1.4 (6.2)	1.9 (7.4)	3.4 (10.7)	3.6 (14.3)	6.6(19.7)
All sites						
Mean	1.6 (4.4)	5.4 (10.1)	12.8 (16.4)	3.7(10.9)	3.9(14.3)	9.0(20.3)
Median	0	2	8	0	1	3

With prophylaxis

	Hemophilia	
	Moderate	Severe
Bleeding site	n = 194	n = 1312
Joint	3.6 (9.1)	3.0 (7.2)
Muscle	0.9 (2.2)	0.8 (2.3)
Other	0.9 (1.9)	1.2 (4.1)
All sites		
Mean	5.4 (10.3)	5.0 (9.6)
Median	2	2

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

Table 7. Liver disease and access infections among persons enrolled in UDC

	Hemophilia n =8650		vWD n =2051	
	Number	% of Total	Number	% of Total
Risk factors for liver disease				
Past/present hepatitis B virus infection	1045	12.1	37	1.8
Past/present hepatitis C virus infection	2347	28.2	105	5.1
History of alcohol abuse	288	3.3	6	0.3
Other	120	1.4	18	0.9
None	5923	68.5	1920	93.6
Signs or symptoms of liver disease (During the last year)				
Jaundice	59	0.7	1	0.1
Ascites	61	0.7	5	0.2
Varices	42	0.5	4	0.2
Other	84	1.0	6	0.3
None	8468	97.9	2037	99.3
Laboratory markers of liver disease				
Chronically elevated ALT/AST levels	1314	15.2	44	2.2
Elevated prothrombin time in the last year	169	2.0	19	0.9
Therapy for chronic viral hepatitis				
Any therapy	491	5.7	25	1.2
Successful therapy	137	28.3*	6	25.0*
Intravenous access devices (IVAD)				
Used an IVAD in the last year	1037	12.0	36	1.8
IVAD infection in the last year	109	10.6**	1	2.8**

*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

Treatment	Mild n (%)	Moderate n (%)	Severe n (%)
Episodic care	2054 (98.7)	1713 (86.5)	2873 (62.6)
Intermittent prophylaxis	16 (0.8)	74 (3.7)	403 (8.8)
Continuous * prophylaxis	11 (0.5)	192 (9.7)	1308 (2.9)
Total	**2081**	**1981**	**4588**

*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	1619	9 (0.5)	4 (0.3)	449	0	0
Moderate	1344	37 (2.8)	18 (1.3)	637	0	2 (0.3)
Severe	3848	139 (3.6)	195 (5.1)	740	10 (1.4)	19 (2.6)

*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 3. Prevalence of natural or acquired immunity to hepatitis A virus among persons with hemophilia enrolled in UDC

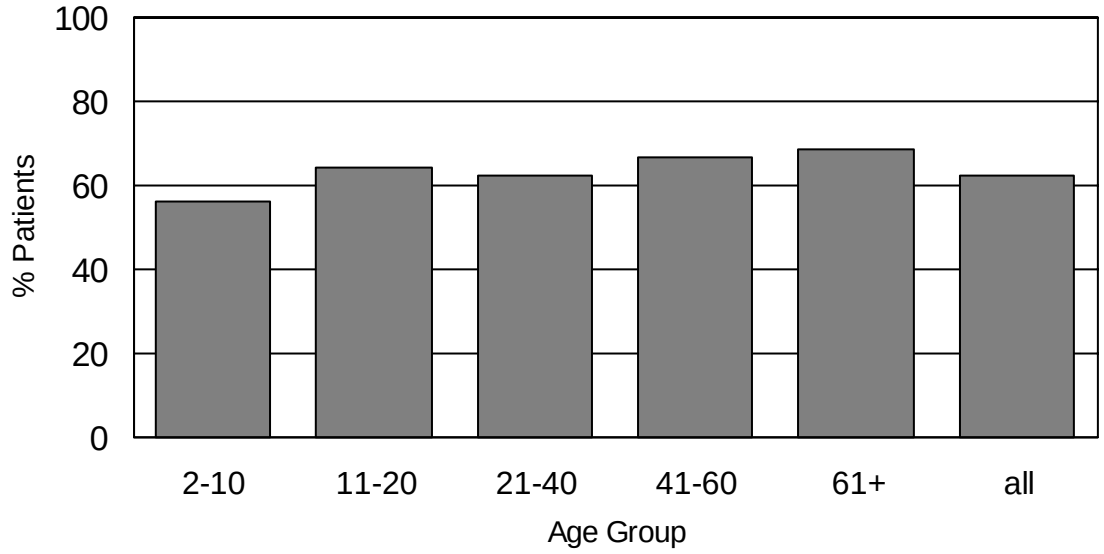

Figure 4. Regional distribution of natural or acquired immunity to hepatitis A virus among persons with hemophilia enrolled in UDC

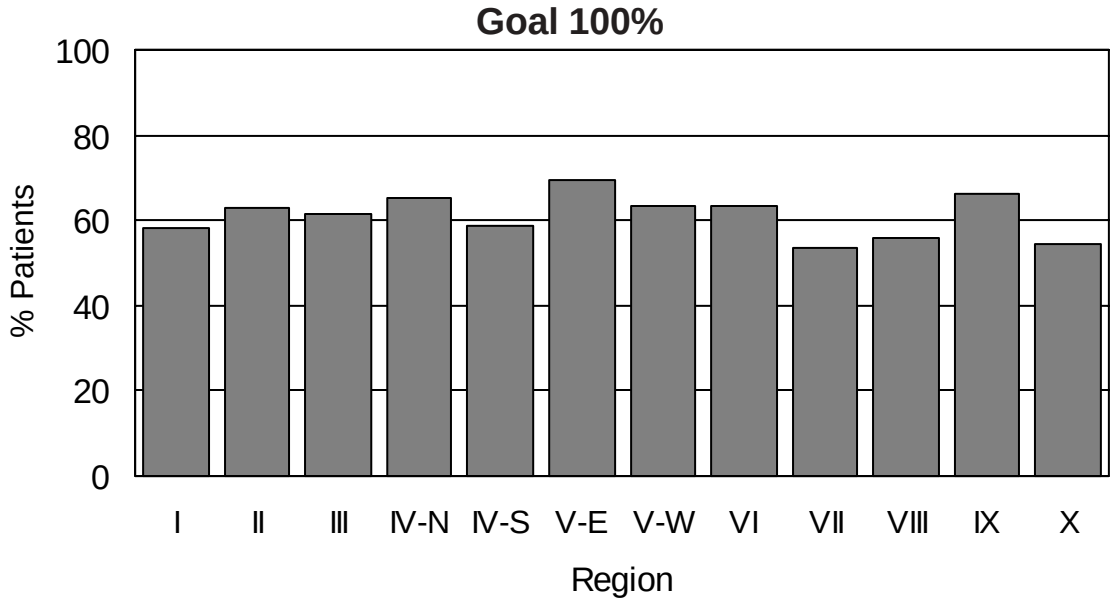

Figure 5. Prevalence of natural or acquired immunity to hepatitis A virus among persons with vWD enrolled in UDC

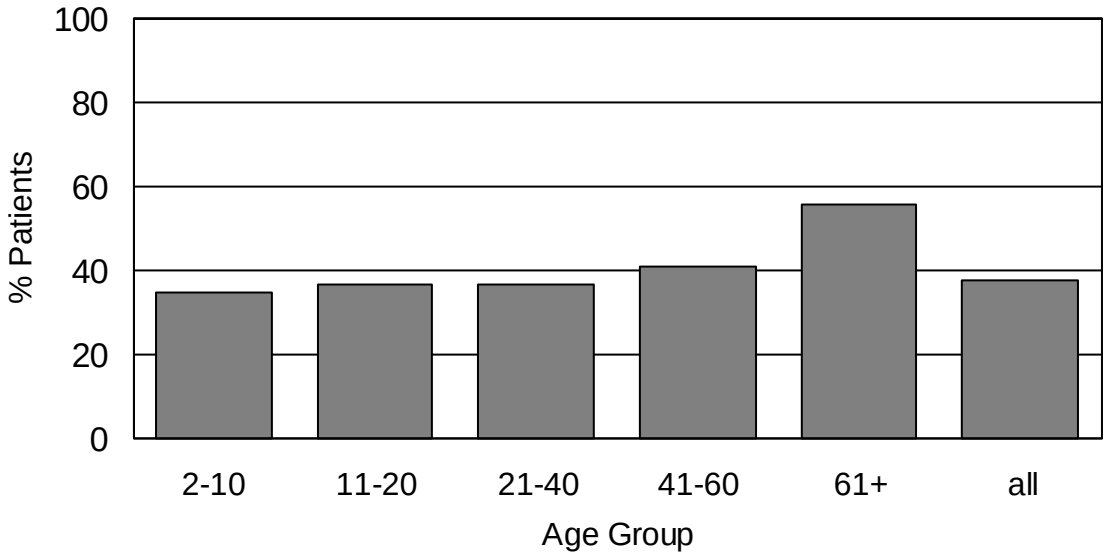

Figure 6. Prevalence of natural or acquired immunity to hepatitis B virus among persons with hemophilia enrolled in UDC

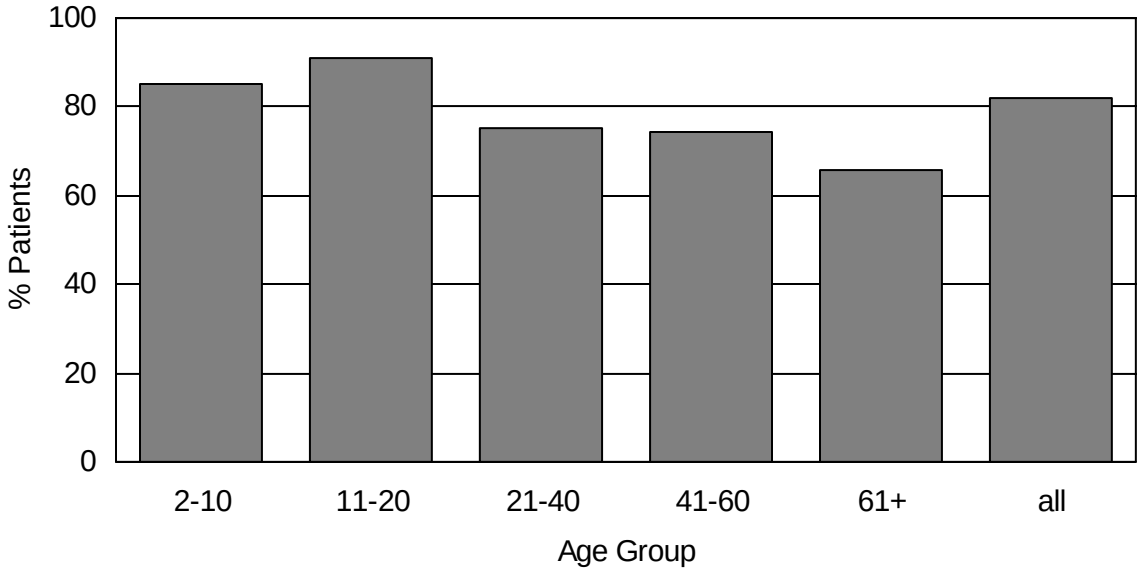

Figure 7. Regional distribution of natural or acquired immunity to hepatitis B virus among persons with hemophilia enrolled in UDC

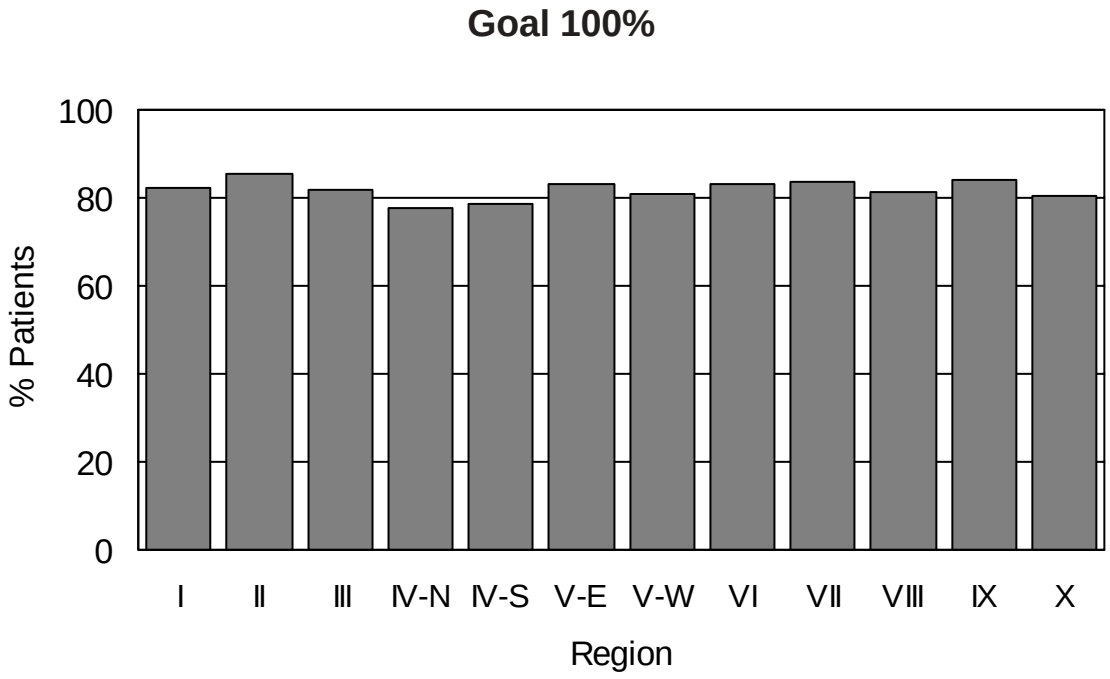

Figure 8. Prevalence of natural or acquired immunity to hepatitis B virus among persons with vWD enrolled in UDC

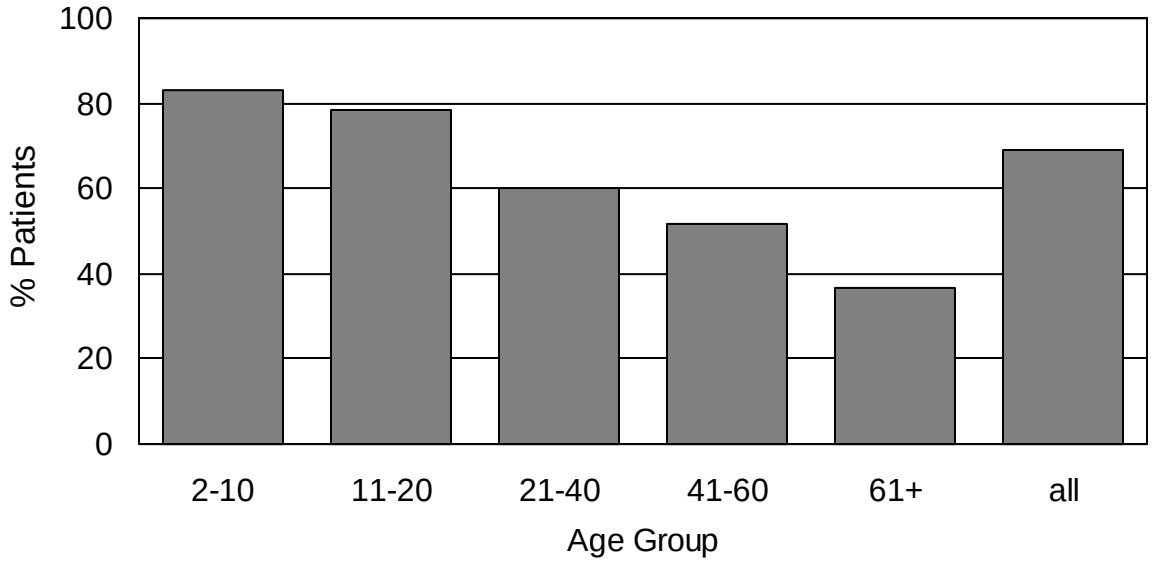

Figure 9. Prevalence of hepatitis C virus infection among persons with bleeding disorders enrolled in UDC

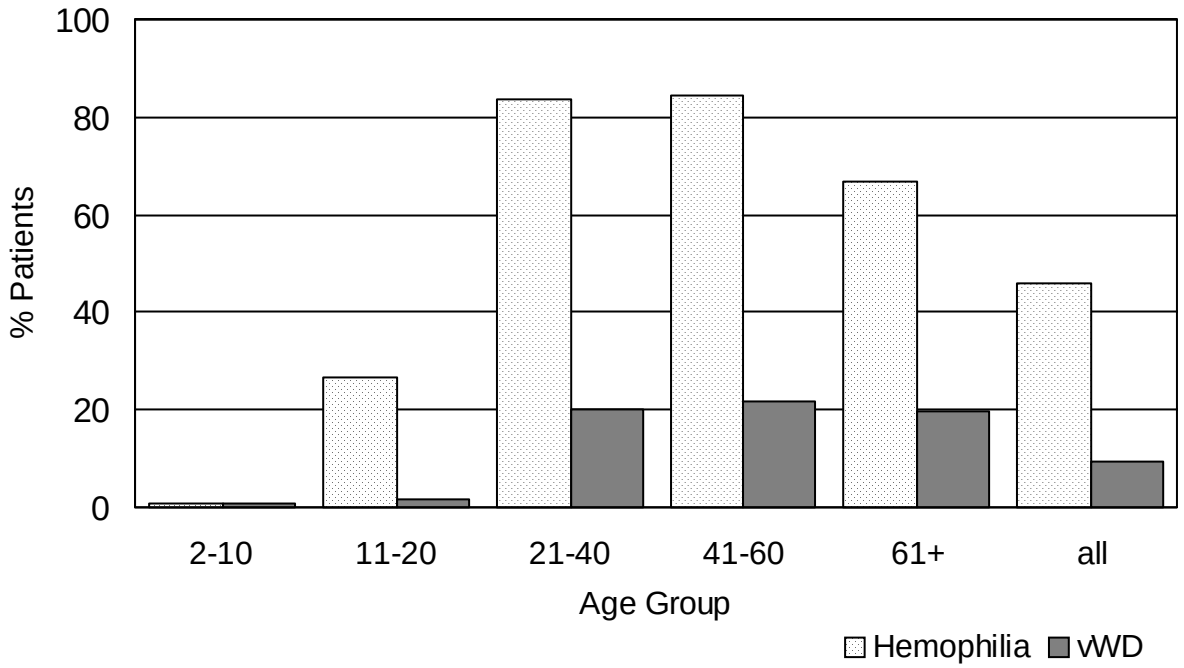

Figure 10. Prevalence of natural or acquired immunity to hepatitis A among hepatitis C-infected persons wth hemophilia enrolled in UDC

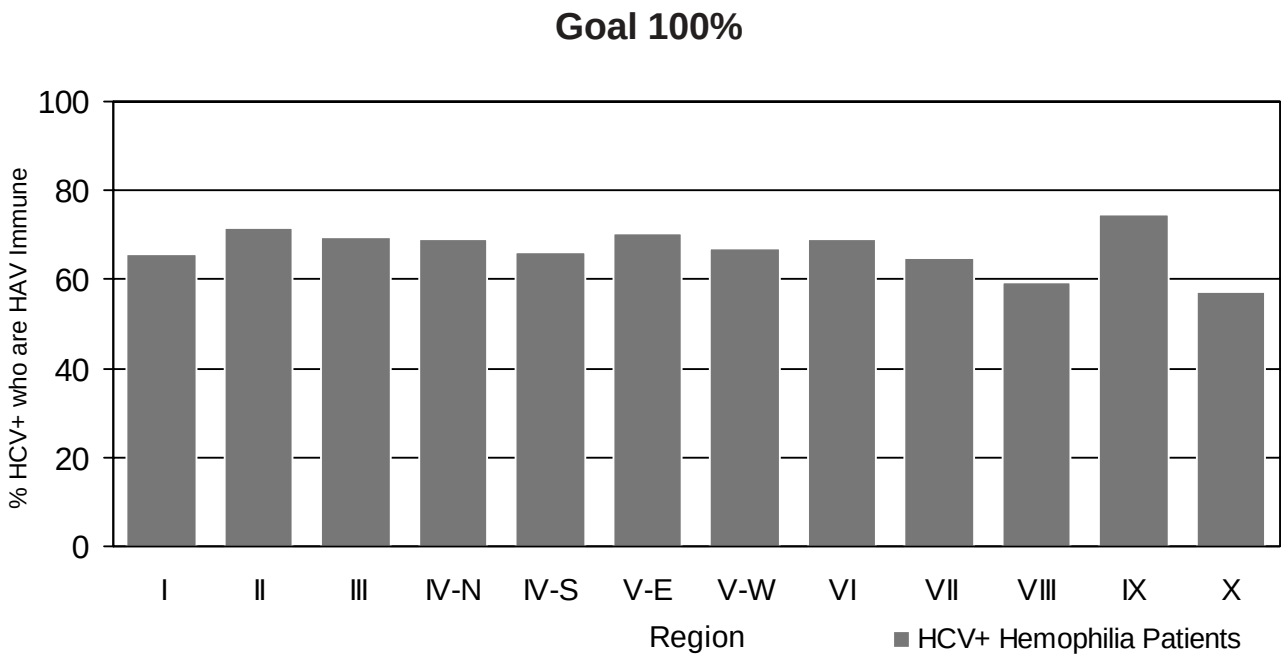

Figure 11. Prevalence of human immunodeficiency virus infection among persons with bleeding disorders enrolled in UDC

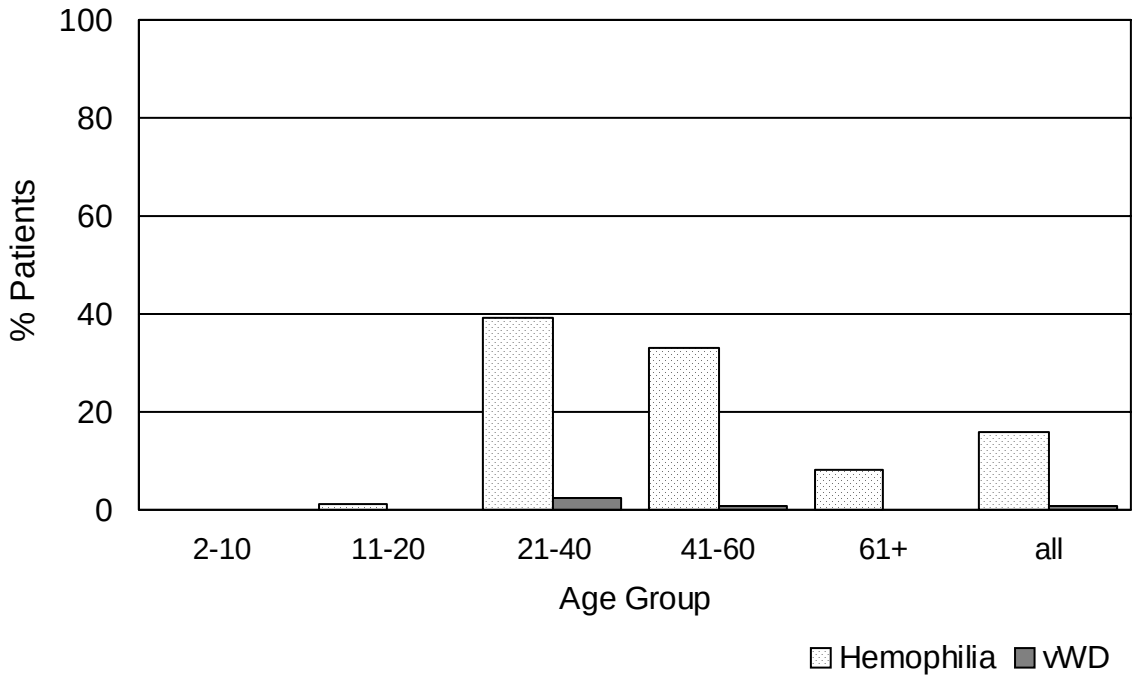

Table 10. Blood and factor products used* by persons enrolled in UDC

	Hemophilia A		Hemophilia B		vWD	
Treatment product	Number	Percent	Number	Percent	Number	Percent
Recombinant factor	4150	60.8	1032	56.5	9	0.4
Monoclonal factor VIII	1383	20.3	7	0.4	5	0.2
Other human factor VIII	152	2.2	2	0.1	422	20.6
Porcine factor VIII	12	0.2	0	—	0	—
Purified factor IX	5	0.1	418	22.9	0	—
Prothrombin complex	34	0.5	32	1.8	0	—
Activated prothrombin complex	259	3.8	17	1.0	1	0.1
Cryoprecipitate or FFP	37	0.5	8	0.4	22	1.1
Desmopressin	518	7.6	4	0.2	836	40.8
None used	811	11.9	381	20.9	766	37.4

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

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

	Hemophilia A		Hemophilia B	
Severity	Total	Number with ICH (%)	Total	Number with ICH (%)
Mild	1632	4 (0.3)	447	2 (0.5)
Moderate	1344	11 (0.8)	635	2 (0.3)
Severe	3847	37 (1.0)	738	4 (0.5)

Causes of ICH	Number (%)
Trauma	34 (60.7)
Thrombocytopenia	2 (3.6)
Other	20 (35.7)

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

Table 12. Joint complications among persons enrolled in UDC

	Hemophilia			vWD		
	Mild n (%)	Moderate n (%)	Severe n (%)	Type 1 n (%)	Type 2 n (%)	Type 3 n (%)
Target joint*	139 (6.7)	499(25.2)	1912(41.7)	31 (2.2)	4 (1.7)	38 (20.4)
Invasive procedure	74 (3.6)	83 (4.2)	456 (9.9)	23 (1.6)	1 (0.4)	17 (9.1)
Joint infection	14 (0.7)	12 (0.6)	51 (1.1)	14 (1.0)	0 —-	0 —-
Used cane	262 (12.6)	399(20.1)	1375 (30.0)	88 (6.2)	9 (3.8)	34(18.3)
Used wheelchair	36 (1.7)	91 (4.6)	431 (9.4)	24 (1.7)	5(2.1)	11(5.9)
Any activity restriction	304 (14.6)	539 (27.2)	1895 (41.3)	123 (8.7)	22(9.4)	51(27.4)

*Please see Technical Notes (page 22) for the definition of a target joint.

Table 13. Joint limitations among persons enrolled in UDC

	Hemophilia			vWD		
	Mild	Moderate	Severe	Type 1	Type 2	Type 3
Number of patients	1920	1784	4007	1330	220	166
Mean indicator* value	52.2	85.0	151.8	20.6	24.8	69.5
Standard deviation	107.0	151.4	212.0	83.7	77.9	113.3

*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 52.2 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 14. Hemophilia A: Percentage of patients age 20 or less on continuous prophylaxis

	Level of Severity			
	Mild	Moderate	Severe	Total
Age Group	n=6	n=142	n=1022	1170
2-5	1 (1.2%)	11 (12.1%)	138 (44.2%)	150
6-10	2 (0.9%)	47 (18.5%)	345 (57.0%)	394
11-15	2 (0.8%)	53 (21.3%)	348 (49.4%)	403
16-20	1 (0.4%)	31 (15.5%)	191 (32.1%)	223
All	**804**	**794**	**2216**	**3814**
Patients on continuous prophylaxis	**0.7 %**	**17.9%**	**46.1%**	**30.6%**

Table 15. Hemophilia B: Percentage of patients age 20 or less on continuous prophylaxis

	Level of Severity			
	Mild	Moderate	Severe	Total
Age Group	n=2	n=32	n=132	166
2-5	1 (3.6%)	2 (4.2%)	21 (32.3%)	24
6-10	1 (1.8%)	11 (12.2%)	46 (39.0%)	58
11-15	0 (0.0%)	13 (12.0%)	42 (39.3%)	55
16-20	0 (0.0%)	6 (6.9%)	23 (21.9%)	29
All	**207**	**333**	**395**	**935**
Patients on continuous prophylaxis	**1.0 %**	**9.6%**	**33.4%**	**17.8%**

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 most current data available from an on-going 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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Region I
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New England Hemophilia Center
Worcester, MA
Yale University School of Medicine
New Haven, CT
Maine Medical Center
Scarborough, ME
Dartmouth-Hitchcock Hemophilia Center
Lebanon, NH
Rhode Island Hospital
Providence, RI
UCONN Hemophilia Treatment Center
Farmington, CT
Vermont Regional Hemophilia Center
Burlington, VT
Boston Children's Hospital
Boston, MA

Region II
Mariam Voutsis, R.N., M.P.A.
The New York Presbyterian Hospital
New York, NY
Puerto Rico Hemophilia Treatment Center
San Juan, PR
UMDNJ-Robert Wood Johnson University Hospital, New Brunswick, NJ
St. Michael's Comprehensive Hemophilia Care Center, Newark, NJ
The Mary M. Gooley Hemophilia Center, Inc. Rochester, NY
SUNY Health Science Center - Adult
Syracuse, NY
SUNY Health Science Center - Pediatric
Syracuse, NY
Hemophilia Center of Western New York – Adult, Buffalo, NY
Hemophilia Center of Western New York – Pediatric, Buffalo, NY
The Regional Comprehensive Hemophilia and von Willebrand Treatment Center
Albany, NY
UHSH Blood Disorders Center
Johnson City, NY
Long Island Jewish Medical Center
New Hyde Park, NY
Mount Sinai Medical Center
New York, NY
Newark Beth Israel Medical Center
Newark, NJ

Region III
Sue Cutter, M.S.W., M.P.A.
Children's Hospital of Philadelphia
Philadelphia, PA
Children's National Medical Center
Washington, DC
Georgetown University Medical Center
Washington, DC
St. Agnes Hospital
Baltimore, MD
University of Virginia Hospital
Charlottesville, VA
Virginia Commonwealth University
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
Lehigh Valley Hospital
Allentown, 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 Specialty Center, Voorhees, NJ
Penn Comprehensive Hemophilia Program Philadelphia, PA

Region IV-N
Richard J. Atwood, M.A., M.P.H.
Wake Forest University School of Medicine Winston-Salem, NC
Norton Kosair Children's Medical Center Louisville, KY
Brown Cancer Center Louisville, KY
Markey Cancer Center Lexington, KY
East Carolina University Greenville, NC
Children's Hospital of Palmetto-Richland Memorial, Columbia, SC
University of Tennessee – Memphis Memphis, TN
East Tennessee Comprehensive Hemophilia Center, Knoxville, TN
Vanderbilt University Medical Center Nashville, TN
University of North Carolina at Chapel Hill Chapel Hill, NC

Region IV-S
Crystal D. Watson, B.S.W.
Nemours Children's Clinic Jacksonville, FL
University of South Florida – Adult Tampa, FL
Miami Comprehensive Hemophilia Center – Pediatrics, Miami, FL
University of Florida Gainesville, FL
Children's Healthcare of Atlanta at Scottish Rite, Atlanta, GA
Medical College of Georgia - Adult Augusta, GA
University of Mississippi Medical Center Jackson, MS
University of Alabama Birmingham Medical Center, Birmingham, AL
Miami Comprehensive Hemophilia Center - Adult, Miami, FL
Children's Rehabilitation Services Mobile, AL
Children's Rehabilitation Services Birmingham, AL
Emory University Hemophilia Program Office Atlanta, GA
Children's Rehabilitation Services Opelika, AL
Children's Rehabilitation Services Huntsville, AL
Medical College of Georgia - Pediatrics Augusta, GA

Region V-E
Tamara Wood-Lively, M.H.A., J.D.
Children's Hospital of Michigan Detroit, MI
Munson Medical Center Traverse City, MI
Hemophilia Clinic of West Michigan Cancer Center, Kalamazoo, MI
Eastern Michigan Hemophilia Treatment Center, Flint, MI
DeVos Children's Hospital at Butterworth Grand Rapids, MI
Ohio State University Medical Center Columbus, OH
Cincinnati Children's Hospital Medical Center Cincinnati, OH
University of Cincinnati Medical Center Cincinnati, OH
Columbus Children's Hospital Columbus, OH
Northwest Ohio Hemophilia Treatment Center, Toledo, OH
Dayton Children's Medical Center Dayton, OH
Indiana Hemophilia and Thrombosis Center Indianapolis, IN
Michigan State University Comprehensive Center for Bleeding Disorders East Lansing, MI
Akron Children's Hospital Medical Center Akron, OH

University of Michigan Hemophilia Treatment Center, Ann Arbor, MI

Region V-W
Mary Anne Schall, R.N., M.S.
Northwestern University Chicago, IL
Cook County Hospital - Adult Chicago, IL
Children's Memorial Hospital Chicago, IL
Comprehensive Bleeding Disorders Center Peoria, IL
Fairview - University Medical Center Minneapolis, MN
Mayo Clinic Rochester, MN
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 Chicago, IL
Michael Reese Hospital – Adult Chicago, IL
South Dakota Children's Specialty Clinics Sioux Falls, SD
Comprehensive Center for Bleeding Disorders, Milwaukee, WI
Cook County Children's Hospital Chicago, IL

Region VI
John Drake, R.N., M.S.N.
Gulf States Hemophilia and Thrombosis Center, Houston, TX
Louisiana Comprehensive Hemophilia Center New Orleans, LA
Hemophilia Center of Arkansas Little Rock, AR
Oklahoma Comprehensive Hemophilia Treatment Center, Oklahoma City, OK
Fort Worth Comprehensive Hemophilia Center, Ft. Worth, TX
North Texas Comprehensive Hemophilia Center – Adult Program, Dallas, TX
South Texas Comprehensive Hemophilia Center, San Antonio, TX
North Texas Comprehensive Hemophilia Center – Pediatric Program, Dallas, TX

Region VII
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University of Iowa Hospitals and Clinics Iowa City, IA
Kansas City Regional Hemophilia Center Kansas City, MO
Nebraska Regional Hemophilia Treatment Center, Omaha, NE
Missouri/Illinois Regional Hemophilia Center St. Louis, MO
Center for Bleeding and Thrombotic Disorders, St. Louis, MO
Hemophilia Treatment Center Columbia, MO

Region VIII
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Mountain States Regional Hemophilia and Thrombosis Center, Denver, CO
Ted R. Montoya Hemophilia Center Albuquerque, NM
Mountain States Regional Hemophilia Center Tucson, AZ
Phoenix Children's Hospital Phoenix, AZ
Mountain States Regional Hemophilia Center Utah, Salt Lake City, UT

Region IX
Judith Baker, M.H.S.A.
Children's Hospital of Los Angeles Los Angeles, CA
University of California San Diego, CA
Lucile Salter Packard Children's Hospital at Stanford, Palo Alto, CA
Alta Bates Medical Center Berkeley, CA
Hemophilia and Thrombosis Center of Hawaii Honolulu, HI
University of California at Davis Sacramento, CA
University of California, San Francisco San Francisco, CA
Orthopaedic Hospital of Los Angeles Los Angeles, CA
Children's Hospital, San Diego San Diego, CA

Children's Hospital of Orange County
Orange, CA
Children's Hospital Oakland
Oakland, CA
City of Hope National Medical Center
Duarte, CA
Guam Comprehensive Hemophilia Care
Program, Agana, GU
Valley Children's Hospital
Madera, CA
Hemophilia and Thrombosis Center of
Las Vegas, Las Vegas, NV

Region X
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Puget Sound Blood Center and Program
Seattle, WA
Oregon Hemophilia Treatment Center
Portland, OR
Alaska Hemophilia Association
Anchorage, AK
Idaho Regional Hemophilia Center
Boise, ID

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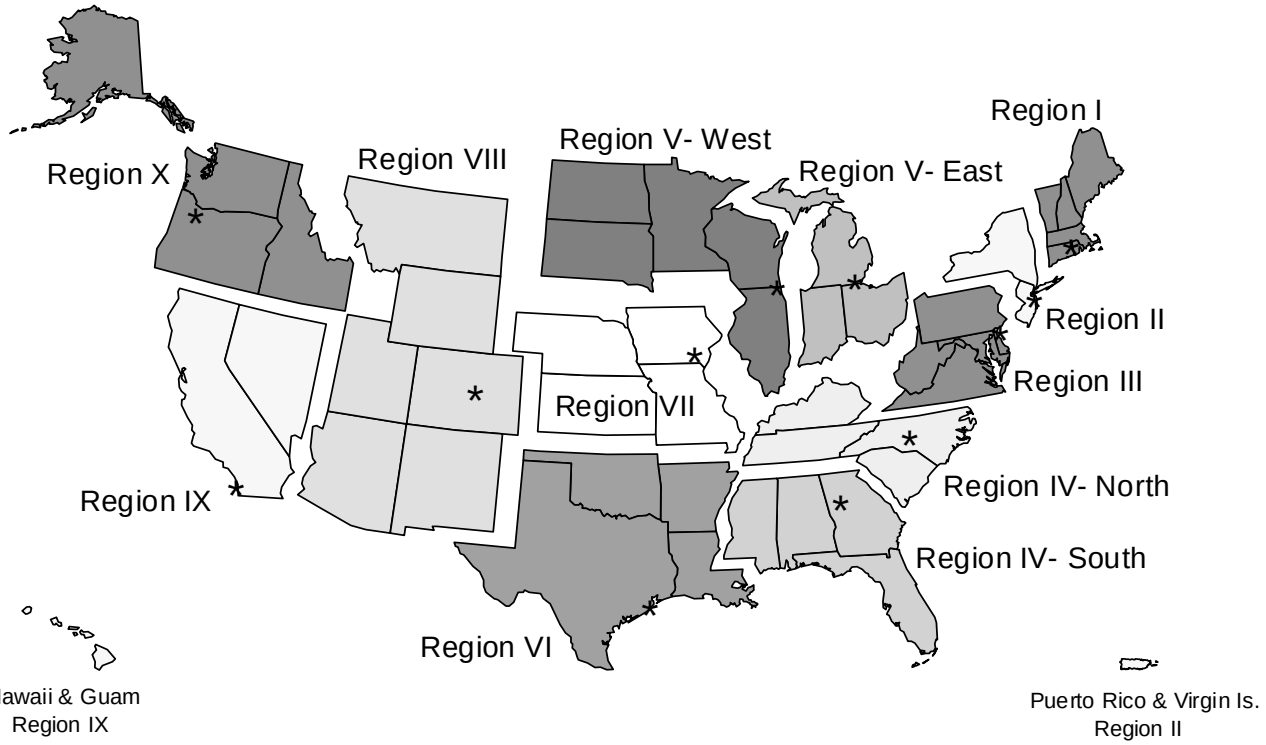
Hemophilia Treatment Center Regions



*Denotes location of regional core centers.