November 1999 / Vol. 1 / No. 2

CDC's Universal Data Collection System

Report on the Universal Data Collection System (UDC)*

Includes data collected from
May 1998 through April 1999
(*revised)

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

CDC
CENTERS FOR DISEASE CONTROL AND PREVENTION

The *Report on the Universal Data Collection System* 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.

Suggested Citation: Centers for Disease Control and Prevention. Report on the Universal Data Collection System, 1999;1(No. 2):[inclusive page numbers].

Single copies of the *Report on the Universal Data Collection System* 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 System* is accessible via internet at http://www.cdc.gov/ncidod/dastlr/Hematology/HDBarchive.htm.

Contents

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 System (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 a 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, and within 6 months, the number of participants had grown to nearly 1,000. Participants were enrolled in 57 HTCs located in 9 of the 12 federal HTC regions. 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 on page 21 in the *Acknowledgements*. A regional map is included on page 24.

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 19.

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 – April 1999

Month	Number Enrolled	Number Refused	Refusal Rate (%)
May	16	0	0
June	115	4	3.4
July	145	12	7.6
August	213	22	9.4
September	229	23	9.1
October	268	30	10.1
November	222	28	11.2
December	218	27	11.0
January	312	25	7.4
February	352	37	9.5
March	367	49	11.8
April	360	39	9.8
Total	**2817**	**296**	**9.5**

Table 2. Regional* enrollment activity, May 1998 – April 1999

Region	Number Approached	Refusal rate (%)
I	150	10.0
II	524	8.8
III	580	15.5
IV-N	262	6.5
IV-S	154	11.0
V-E	98	14.3
V-W	466	6.7
VI	339	10.9
VII	31	12.9
VIII	149	4.0
IX	358	5.3
X	2	0

*See map (page 24) for regional designations.

Table 3. Demographic characteristics of persons* enrolled in UDC

Characteristic	Hemophilia A (n = 1939) Number	Hemophilia A (n = 1939) Percent	Hemophilia B (n = 443) Number	Hemophilia B (n = 443) Percent	vWD (n = 382) Number	vWD (n = 382) Percent
Age Group (years)						
2 – 10	549	28.4	112	25.4	115	30.1
11 – 20	577	29.9	114	25.9	132	34.6
21 – 40	475	24.6	140	31.7	72	18.8
41 – 60	284	14.7	60	13.6	45	11.8
61+	46	2.4	15	3.4	18	4.7
Race / Ethnicity						
White	1293	66.7	330	74.5	257	67.3
African American	253	13.0	53	12.0	20	5.2
Hispanic	251	12.9	46	10.4	45	11.8
Asian / Pacific Islander	55	2.8	**	—	9	2.4
Native American	14	0.7	**	—	**	—
Other	73	3.8	9	2.0	47	12.3
Sex						
Male	1902	98.1	437	98.6	179	46.9
Female	37	1.9	6	1.4	203	53.1

*Thirteen persons were reported to have both hemophilia and vWD, and 62 persons had a bleeding disorder other than hemophilia or vWD.

**Number suppressed because of small cell sizes.

Table 4. Disease severity of persons enrolled in UDC

	Hemophilia Mild N	Hemophilia Mild %	Hemophilia Moderate N	Hemophilia Moderate %	Hemophilia Severe N	Hemophilia Severe %	vWD Type 1 & 2 N	vWD Type 1 & 2 %	vWD Type 3 N	vWD Type 3 %
Participants*	444	18.7	565	23.8	1360	57.4	295	86.3	47	13.7

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

Table 5. Bleeding episodes* among persons enrolled in UDC by disease severity and prophylaxis status

No prophylaxis

	Hemophilia			vWD	
	Mild	Moderate	Severe	Type 1 & 2	Type 3
Bleeding site	n = 441	n = 514	n = 1045	n = 283	n = 46
Joint	0.6 (2.4)	3.6 (7.4)	9.2 (11.8)	0.3 (2.0)	4.3 (9.8)
Muscle	0.3 (1.1)	1.0 (2.3)	2.5 (4.6)	0.2 (1.0)	0.4 (1.3)
Other	0.8 (3.1)	1.2 (3.7)	1.9 (4.2)	3.7 (10.4)	3.4 (4.8)
All sites					
Mean	1.7 (4.5)	5.8 (9.8)	13.6 (14.0)	4.1 (10.6)	8.2 (11.3)
Median	0	3	10	1	4

With prophylaxis

	Hemophilia		
	Mild	Moderate	Severe
Bleeding site	N = 3	n = 49	n = 315
Joint	0.7 (1.2)	2.4 (3.4)	3.5 (6.2)
Muscle	0 (—)	0.8 (2.5)	0.9 (2.4)
Other	0.7 (1.2)	1.3 (3.8)	1.8 (7.9)
All sites			
Mean	1.3 (1.2)	4.5 (7.0)	6.2 (10.9)
Median	2	2	3

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

Table 6. 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	1180	60.9	226	51.0	3	0.8
Monoclonal factor VIII	401	20.7	1	0.2	1	0.3
Other human factor‘	117	6.0	1	0.2	84	22.8
Porcine factor VIII	5	0.3	0	—	0	—
Purified factor IX	1	0.1	163	36.8	0	—
Prothrombin complex	41	2.1	17	3.8	0	—
Activated prothrombin complex	91	4.7	5	1.1	0	—
Cryoprecipitate or FFP	8	0.4	3	0.7	9	2.4
Desmopressin	105	5.4	1	0.2	117	31.7
None used	175	9.0	78	17.6	143	38.8

*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 7. Infectious disease complications among persons enrolled in UDC

	Hemophilia		vWD	
Infectious Disease Complications	Number	% of Total	Number	% of Total
Risk factors for liver disease				
Past/present hepatitis B virus infection	491	20.6	17	4.5
Past/present hepatitis C virus infection	1163	48.8	37	9.7
History of alcohol abuse	95	4.0	1	0.3
Other	18	0.8	6	1.6
None	1163	48.8	336	88.0
Signs or symptoms of liver disease (During the last year)				
Jaundice	16	0.7	1	0.3
Ascites	17	0.6	1	0.3
Varices	11	0.5	0	—
Other	26	1.1	0	—
None	2324	97.6	380	99.5
Laboratory markers of liver disease				
Chronically elevated ALT/AST levels	452	19.0	8	2.1
Elevated prothrombin time in the last year	66	2.8	5	1.3
Therapy for chronic viral hepatitis				
Any therapy	104	4.4	4	1.0
Successful therapy	23	22.1*	1	25.0*
Intravenous access devices (IVAD)				
Used an IVAD in the last year	304	12.8	15	3.9
IVAD infection in the last year	50	16.4**	1	6.7**

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

Figure 1. Prevalence of hepatitis A virus exposure and reported vaccination status among persons with hemophilia

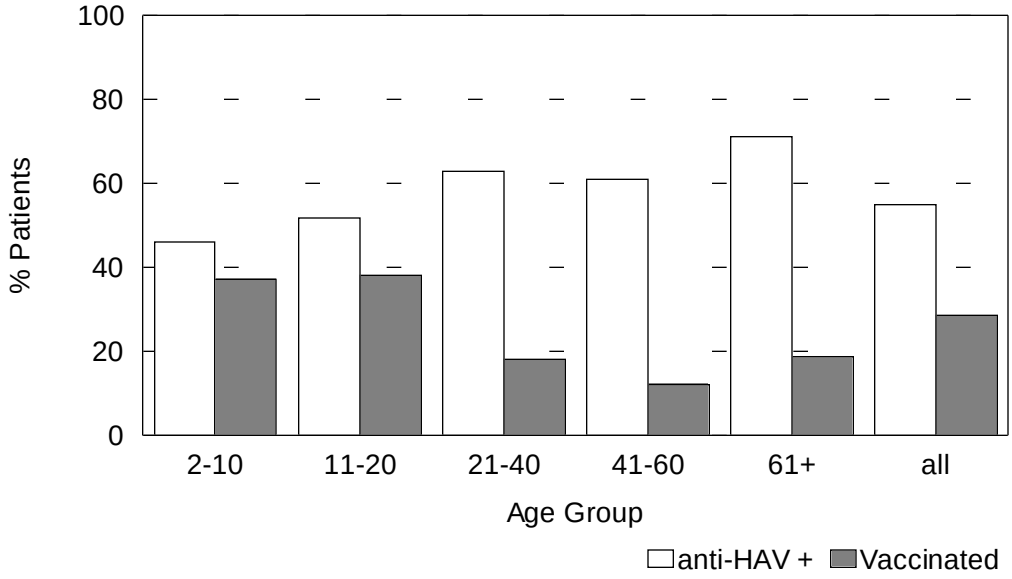
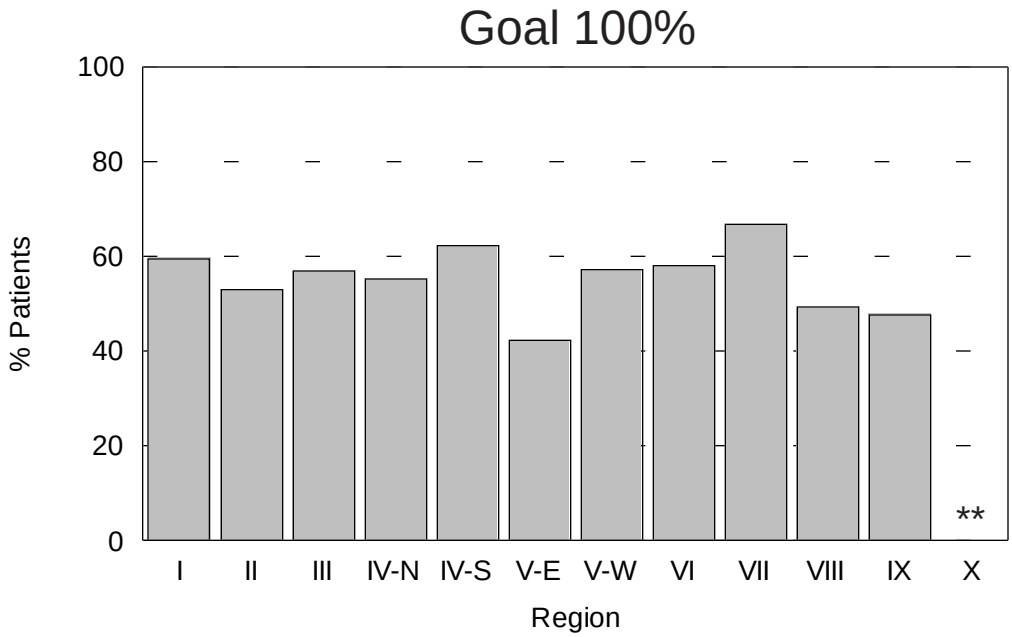


Figure 2. Regional* distribution of natural and acquired immunity to hepatitis A virus among persons with hemophilia



*See map (page 24) for regional designations.

**No results available

Figure 3. Prevalence of hepatitis A virus exposure and reported vaccination status among persons with vWD

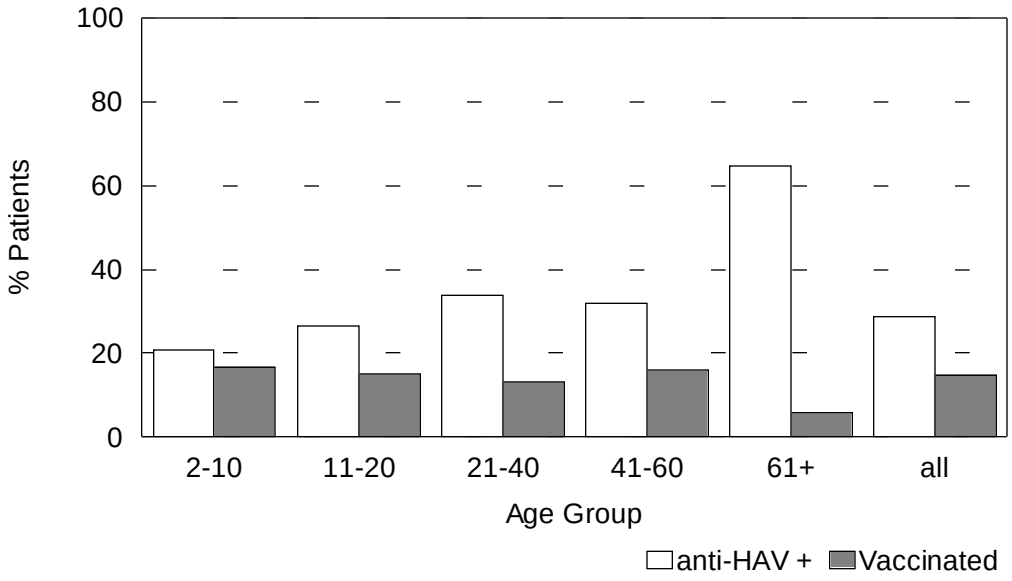


Figure 4. Prevalence of hepatitis B virus exposure and reported vaccination status among persons with hemophilia

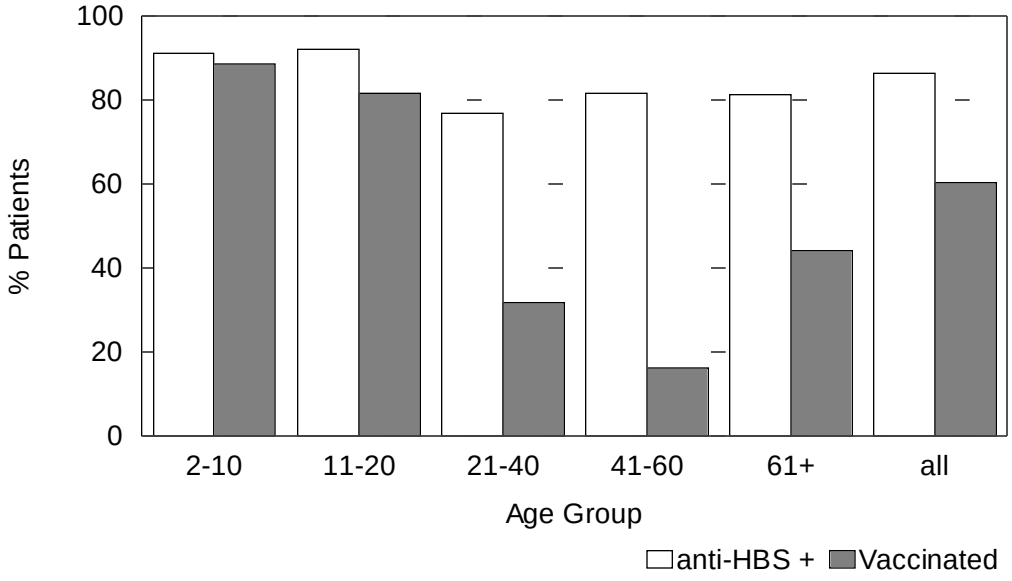
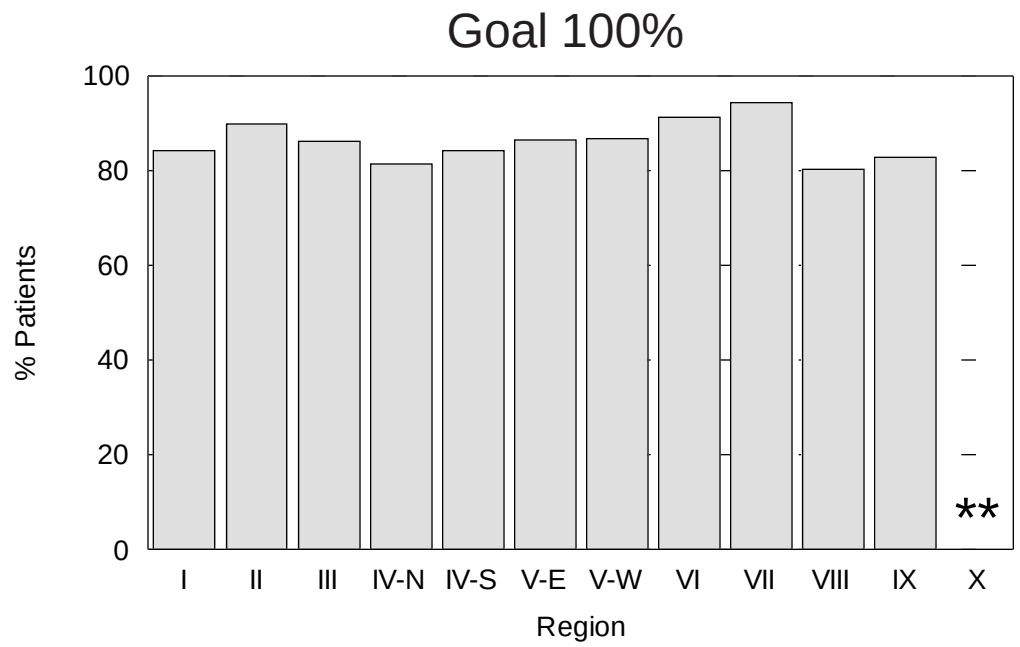


Figure 5. Regional* distribution of natural and acquired immunity to hepatitis B virus among persons with hemophilia



*See map (page 24) for regional designations.
**No results available

Figure 6. Prevalence of hepatitis B virus exposure and reported vaccination status among persons with vWD

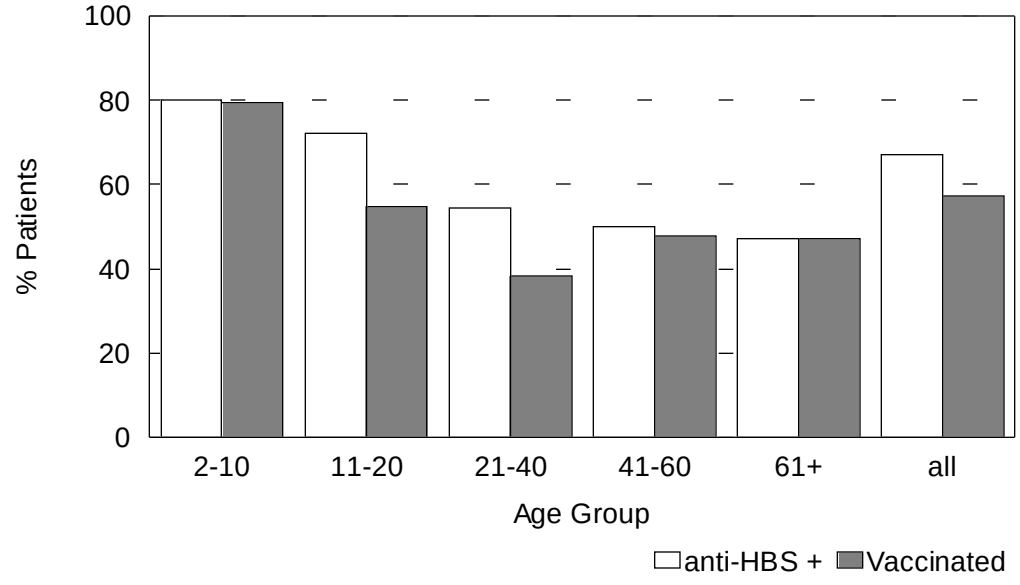


Figure 7. Prevalence of hepatitis C virus infection among persons with bleeding disorders

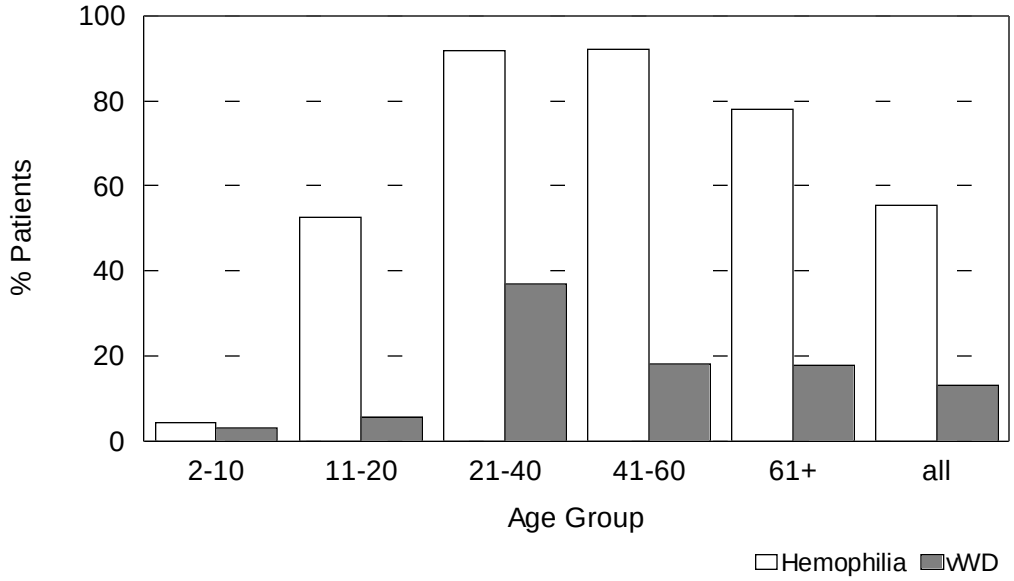


Figure 8. Prevalence of human immunodeficiency virus (HIV) infection among persons with hemophilia

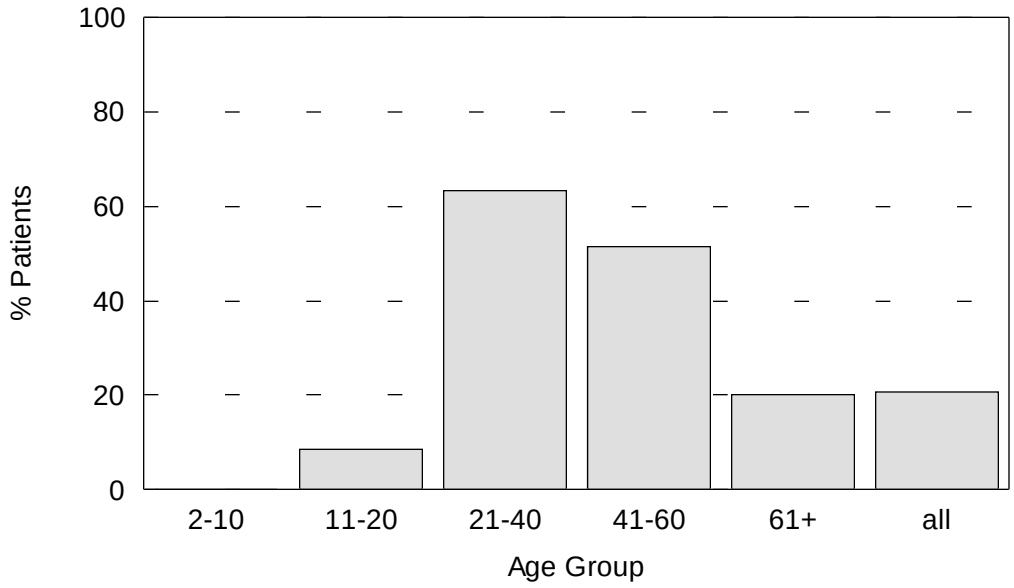


Table 8. Treatment type for persons with hemophilia enrolled in UDC

Severity	Total number	Episodic care No. (%)	Number on intermittent prophylaxis	Number on continuous* prophylaxis
Mild	444	438 (99.3)	3	3
Moderate	565	494 (95.7)	22	49
Severe	1360	933 (89.3)	113	315

*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	357	1 (0.3)	1 (0.3)	87	0	0
Moderate	411	8 (2.0)	6 (1.5)	154	0	0
Severe	1159	45 (3.9)	73 (6.3)	201	2 (1.0)	7 (3.5)

*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 Bethesda units (BU).
Numbers in parentheses are percents.

Table 10. Intra-cranial hemorrhage (ICH)* among persons with hemophilia enrolled in UDC

	Hemophilia A		Hemophilia B	
Severity	Total	No. with ICH (%)	Total	No. with ICH (%)
Mild	357	1 (0.3)	87	0
Moderate	411	3 (0.7)	154	0
Severe	1159	15 (1.3)	201	1 (0.5)

Causes of ICH	Number (%)
Trauma	12 (66.7)
Thrombocytopenia	1 (5.6)
Other	5 (27.8)

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

Table 11. Joint complications among persons enrolled in UDC

	Hemophilia						vWD			
	Mild		Moderate		Severe		Type 1 & 2		Type 3	
	N	%	N	%	N	%	N	%	N	%
Target joint*	44	9.9	180	31.9	672	49.4	3	1.1	10	21.3
Invasive procedure	17	3.8	38	6.7	171	12.6	5	1.8	3	6.4
Joint infection	3	0.7	9	1.6	28	2.1	0	—	0	—
Used cane	63	14.2	131	23.2	430	31.6	12	4.2	9	19.1
Used wheelchair	10	2.2	31	5.5	148	10.9	9	3.2	3	6.4
Any activity restriction	59	13.3	181	32.0	572	42.0	23	8.1	13	27.7

*Please see Technical Notes (page 19) for the definition of a target joint.

Table 12. Joint limitations among persons enrolled in UDC

	Hemophilia			vWD	
	Mild	Moderate	Severe	Type 1 & 2	Type 3
Number of patients	419	516	1187	272	46
Mean indicator* value	56.6	107.6	159.0	32.2	68.3
Standard deviation	97.1	177.6	221.9	77.2	120.2

*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 56.6 degrees less than normal range of motion across ten joints.

Table 13. Causes of death among persons with hemophilia or vWD who died in 1998

	Hemophilia A		Hemophilia B		vWD	
Causes*	Number	Percent	Number	Percent	Number	Percent
Hemophilia / vWD-related	14	12.1	4	21.1	0	—
HIV-related	49	42.2	4	21.1	0	—
Liver disease-related	19	16.4	5	26.3	2	28.6
Suicide	1	0.9	2	10.5	0	—
Other	23	19.8	1	5.3	5	71.4
Unknown	10	8.6	3	15.8	0	—
Totals	116		19		7	

*Causes of death were categorized by treatment center staff using cause of death information available to them either from death records, physician report, or family report.

Figure 9. Age at death among persons with hemophilia or vWD who died in 1998

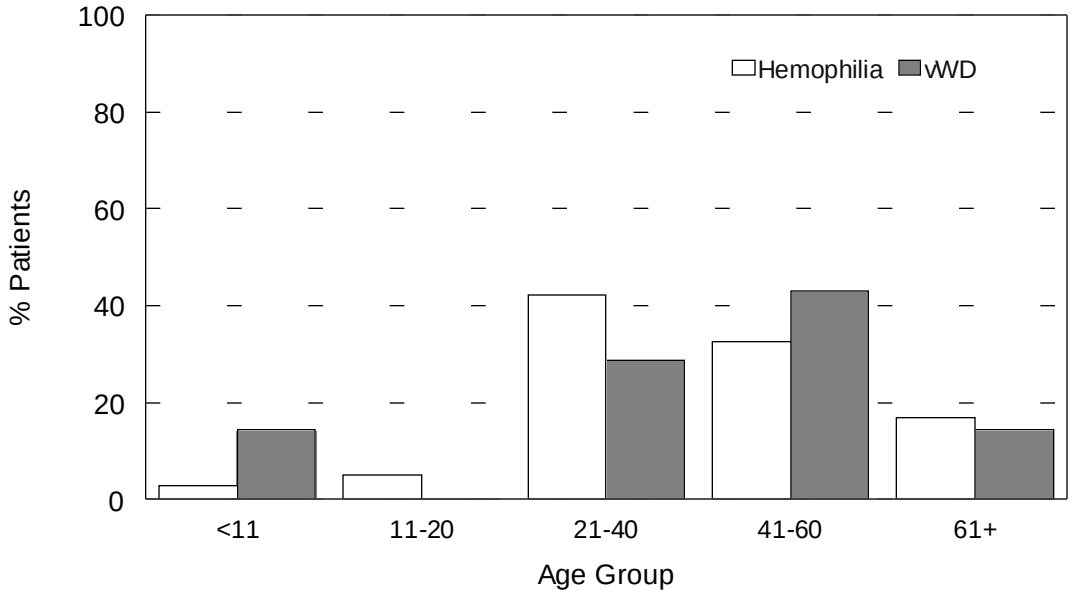
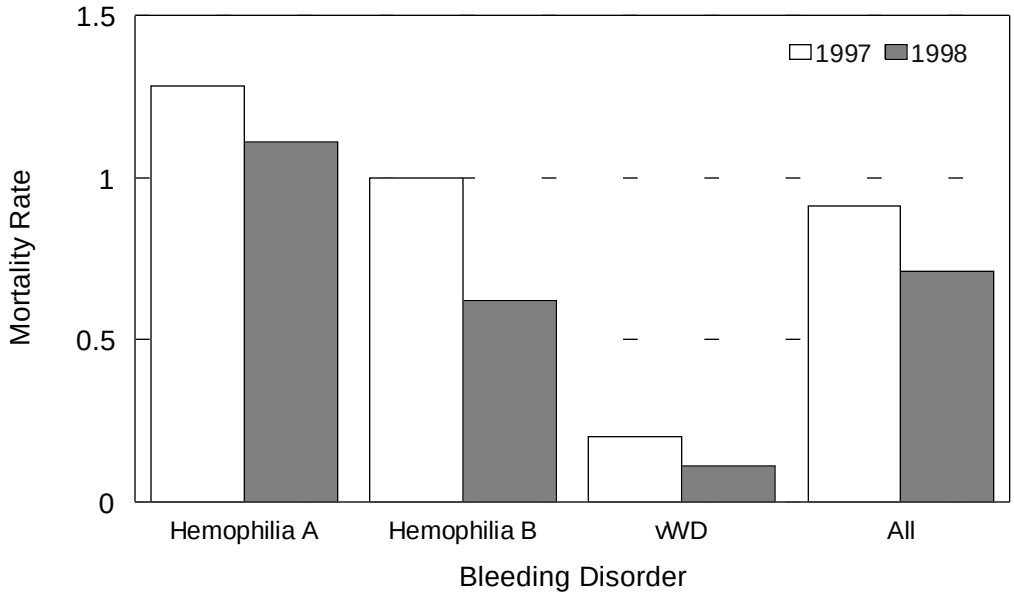


Figure 10. Disease-specific mortality rates* based on persons with hemophilia or vWD who died in 1997 or 1998



*Mortality rate is the number of deaths per 100 active patients followed. The numerator is the number of deaths that occurred among persons in the disease group reported on Mortality forms, and the denominator is the number of active patients in each disease group followed by HTCs as reported in the CDC Hemophilia Data Set (HDS).

NOTE: This is a crude mortality rate that is not adjusted for differences that may exist between disease groups in the distributions of patients by age, disease severity, and other factors related to mortality.

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 blood products used, and whether or not 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 12 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.

Acknowledgements

We thank the Regional Coordinators (listed below in italics) of the federal HTC regions for their assistance in the implementation and technical support of UDC. Data for this report were collected by care providers in HTCs at the following institutions:

Region I
Ann Forsberg, M.A., M.P.H.
New England Hemophilia Center
Worcester, MA
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 Hospital
New York, NY
Puerto Rico Hemophilia Treatment Center
San Juan, PR
UMDNJ-Robert Wood Johnson University
Hospital, New Brunswick, NJ
Nadeene Brunini 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
Albany Medical College
Albany, NY
UHSH Blood Disorders Center
Johnson City, NY
Mount Sinai Medical Center
New York, NY

Region III
Sue Cutter, M.S.W., M.P.A.
Children's National Medical Center
Washington, DC
Georgetown University Medical Center
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

Region IV-N
Richard J. Atwood, M.A., M.P.H.
Wake Forest University School of Medicine
Winston-Salem, NC
Brown Cancer Center
Louisville, KY
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.
Miami Comprehensive Hemophilia Center – Pediatrics, Miami, FL
University of Florida Gainesville, FL
Scottish Rite Children's Medical Center Atlanta, GA
Medical College of Georgia - Adult Augusta, GA
University of Mississippi Medical Center Jackson, MS
Miami Comprehensive Hemophilia Center - Adult, Miami, FL
Children's Rehabilitation Services Mobile, AL
Children's Rehabilitation Services Birmingham, AL
Children's Rehabilitation Services Opelika, AL
Children's Rehabilitation Services Huntsville, AL
Emory University Hemophilia Program Atlanta, GA

Region V-E
Tamara Wood-Lively, M.H.A., J.D.
Munson Medical Center Traverse City, MI
Hemophilia Clinic of West Michigan Cancer Center, Kalamazoo, MI
University of Cincinnati Medical Center Cincinnati, OH
The Children's Medical Center Dayton, OH
Michigan State University Comprehensive Center for Bleeding Disorders East Lansing, 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
Arkansas Children's Hospital Little Rock, AR
Oklahoma Comprehensive Hemophilia Treatment Center, Oklahoma City, OK
Cook Children's Medical Center Ft. Worth, TX
South Texas Comprehensive Hemophilia Center, San Antonio, TX

Region VII
Mike Lammer, MSW
University of Iowa Hospitals and Clinics
Iowa City, IA

Region VIII
Mary Lou Damiano, R.N., M.Ed.
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

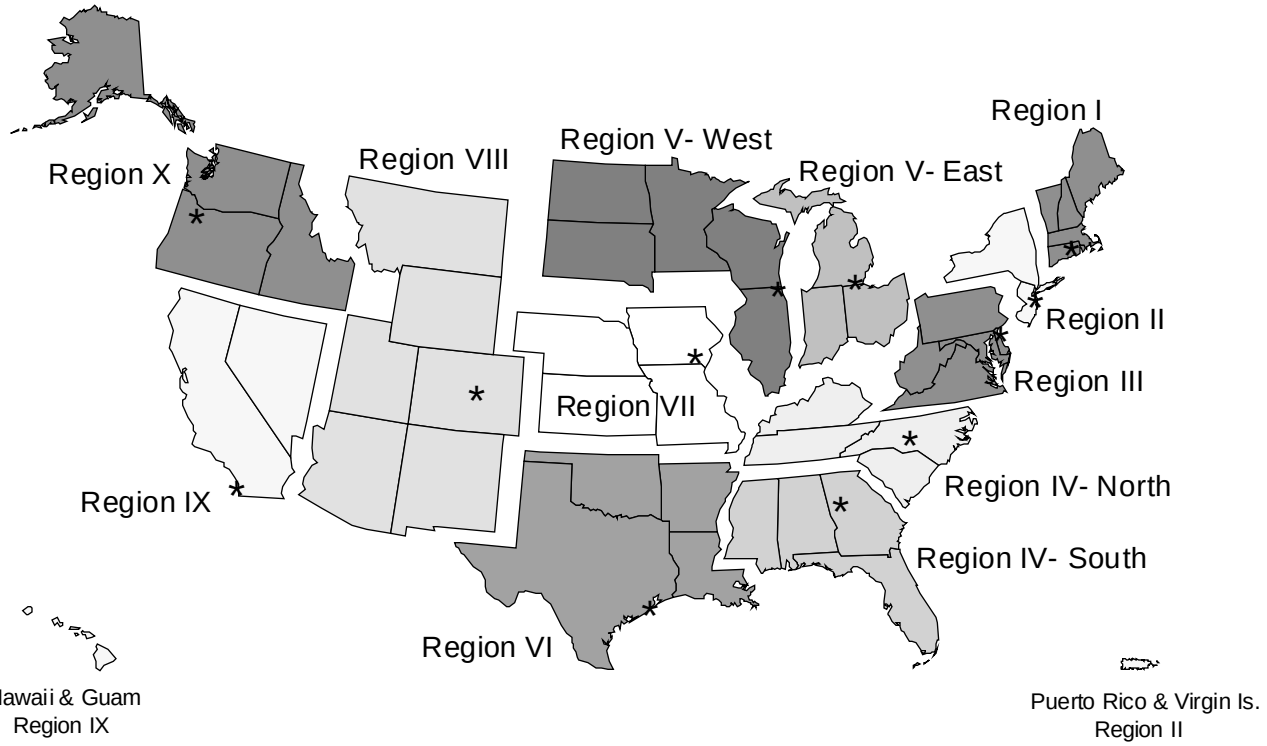
Region IX
Judith Baker, M.H.S.A.
Children's Hospital of Los Angeles
Los Angeles, CA
Alta Bates Medical Center
Berkeley, CA
University of California at Davis
Sacramento, CA
University of California, San Francisco
San Francisco, CA
Orthopaedic Hospital of Los Angeles
Los Angeles, CA
Children's Hospital, San Diego
San Diego, CA
Children's Hospital of Orange County
Orange, CA
Children's Hospital Oakland
Oakland, CA
Hemophilia and Thrombosis Center of Nevada, Las Vegas, NV
Guam Comprehensive Hemophilia Care Program, Agana, GU

Region X
Robina Ingram-Rich, R.N., M.S., M.P.H.
Puget Sound Blood Center and Program
Seattle, WA

We would also like to acknowledge the assistance of the UDC Working Group comprised of the following individuals:

Randall Curtis, M.B.A
Berkeley, CA
Bruce Ewenstein, M.D.
Boston, MA
Ann Forsberg, M.A., M.P.H.
Worcester, MA
Sue Geraghty, R.N., M.B.A.
Aurora, CO
W. Keith Hoots, M.D.
Houston, TX
Heather Huszti, Ph.D.
Oklahoma City, OK
Marion Koerper, M.D.
San Francisco, CA
Jeanne Lusher, M.D.
Detroit, MI
Peter Smith, M.D.
Providence, RI
Scott Ward, RPT, Ph.D.
Salt Lake City, UT
Gilbert C, White, II, M.D.
Chapel Hill, NC

Hemophilia Treatment Center Regions



*Denotes location of regional core centers.