Report on the Universal Data Collection System (UDC)

March 1999 Vol. 1, No. 1

Includes UDC participants from May through October 1998

Contents

Commentary....3

Tables

Table 1. Enrollment in UDC, May - October 1998....5
Table 2. Demographic characteristics of persons enrolled in UDC....5
Table 3. Disease severity of persons enrolled in UDC....6
Table 4. Bleeding episodes among persons enrolled in UDC by disease severity....6
Table 5. Blood and factor products used by persons enrolled in UDC....6
Table 6. Infectious disease complications among persons enrolled in UDC....7
Table 7. Joint complications among persons enrolled in UDC....12
Table 8. Joint limitations among persons enrolled in UDC....12
Table 9. Causes of death among all persons with bleeding disorders who died in 1997....13

Figures

Figure 1. Prevalence of hepatitis A virus exposure and reported vaccination status among persons with hemophilia....8
Figure 2. Regional distribution of natural and acquired immunity to hepatitis A virus among persons with hemophilia....8
Figure 3. Prevalence of hepatitis A virus exposure and reported vaccination status among persons with von Willebrand disease....9
Figure 4. Prevalence of hepatitis B virus exposure and reported vaccination status among persons with hemophilia....9
Figure 5. Regional distribution of natural and acquired immunity to hepatitis B virus among persons with hemophilia....10
Figure 6. Prevalence of hepatitis B virus exposure and reported vaccination status among persons with von Willebrand disease....10
Figure 7. Prevalence of hepatitis C virus infection among persons with hemophilia or von Willebrand disease....11
Figure 8. Prevalence of human immunodeficiency virus (HIV) infection among persons with hemophilia....11
Figure 9. Age at death among all persons with bleeding disorders who died in 1997....13
Figure 10. Disease-specific mortality rates based on all persons with bleeding disorders who died in 1997....11

Technical Notes....15
Acknowledgments....17
Hemophilia Treatment Center Regional Map....19

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Public Health Service
Centers for Disease Control and Prevention
National Center for Infectious Diseases
Atlanta, Georgia 30333

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. 1):[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 www.cdc.gov.

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 is 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 with 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 occurence 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 specimen 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 in the Acknowledgments. A regional map is included on page 19.

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 15.

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 - October 1998.

Month (1998)	Number enrolled	Number refused	Refusal rate (%)
May	16	0	0
June	114	5	4.2
July	145	14	8.8
August	210	22	9.5
September	224	21	8.6
October	238	29	10.9
Total	947	91	8.8

Table 2. Demographic characteristics of persons* enrolled in UDC.

	Hemophilia		vWD	
Characteristic	Number	Percent	Number	Percent
Age Group (years)				
2 - 10	262	31.4	31	33.0
11 - 20	291	34.8	21	22.3
21 - 40	156	18.7	22	23.4
41 - 60	109	13.1	14	14.9
61+	17	2.0	6	6.4
All	835	100	94	100
Race / Ethnicity				
White	531	63.6	66	70.2
African American	90	10.8	3	3.2
Hispanic	134	16.1	15	16.0
Asian / Pacific Islander	35	4.2	6	6.4
Native American	5	0.6	2	2.1
Other	40	4.8	2	2.1
Sex				
Male	827	99.9	43	45.7
Female	8	0.1	51	54.3

*Four persons were reported to have both hemophilia and vWD, and 22 persons had a bleeding disorder other than hemophilia or vWD.

Table 3. Disease severity of persons enrolled in UDC.

	Hemophilia						vWD			
	Mild		Moderate		Severe		Type 1 & 2		Type 3	
	N	%	N	%	N	%	N	%	N	%
Participants*	137	16.5	192	23.1	503	60.5	64	75.3	21	24.7

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

Table 4. Bleeding episodes* among persons enrolled in UDC by disease severity.

	Hemophilia			vWD	
	Mild	Moderate	Severe	Type 1 & 2	Type 3
Bleeding site	N =137	N = 192	N =502	N = 61	N = 21
Joint	0.5 (1.1)	4.5 (7.7)	7.9 (9.6)	0.3 (1.6)	4.1 (8.6)
Muscle	0.2 (0.5)	1.0 (2.4)	2.2 (4.4)	0.2 (0.9)	0.1 (0.3)
Other	0.5 (1.2)	1.2 (3.4)	2.1 (6.1)	2.8 (7.6)	2.9 (3.7)
All Mean	1.1 (2.0)	6.6 (10.7)	12.2 (13.0)	3.3 (7.9)	7.1 (8.7)
Median	0	3	8	0	4

*Values are mean (±SD) number of bleeding episodes experienced during the 6-month period preceding UDC enrollment. Includes 142 persons with hemophilia and 1 person with vWD on continuous prophylaxis.

Table 5. Blood and factor products used* by persons enrolled in UDC.

	Hemophilia A (n=697)		Hemophilia B (n=138)		vWD (n=90)	
Treatment Product	N	%	N	%	N	%
Recombinant factor	423	60.7	51	37.0	1	1.1
Monoclonal factor VIII	144	20.6	1	0.7	0	-
Other human factor VIII	60	8.6	0	-	27	30.0
Porcine factor VIII	1	0.1	0	-	0	-
Purified factor IX	1	0.1	62	44.9	0	-
Prothrombin complex	10	1.4	2	1.4	0	-
Activated prothrombin complex	28	4.0	3	2.2	0	-
Cryoprecipitate or FFP	2	0.3	1	0.7	3	3.3
Desmopressin	35	5.0	1	0.7	26	28.9
None used	45	6.4	27	19.6	30	33.3

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

Table 6. Infectious disease complications among persons enrolled in UDC.

Infectious Disease Complications	Hemophilia (n=835)		vWD (n=94)	
	Number	% of Total	Number	% of Total
Risk factors for liver disease				
Past/present hepatitis B virus infection	160	19.2	3	3.2
Past/present hepatitis C virus infection	404	48.4	10	10.6
History of alcohol abuse	26	3.1	0	-
Other	4	0.5	3	3.2
None	414	49.6	81	86.2
Signs or symptoms of liver disease (during the last year)				
Jaundice	6	0.7	0	-
Ascites	7	0.8	0	-
Varices	3	0.4	0	-
Other	10	1.2	0	-
None	811	97.1	94	100.0
Laboratory markers of liver disease				
Chronically elevated ALT/AST levels	136	16.3	2	2.1
Elevated prothrombin time in the last year	23	2.8	1	1.1
Therapy for chronic viral hepatitis				
Any therapy	37	4.4	1	1.1
Successful therapy	11	29.7*	0	0.0
Intravenous access devices (IVAD)				
Used an IVAD in the last year	108	13.0	6	6.5
IVAD infection in the last year	18	17.5**	0	0.0

*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.

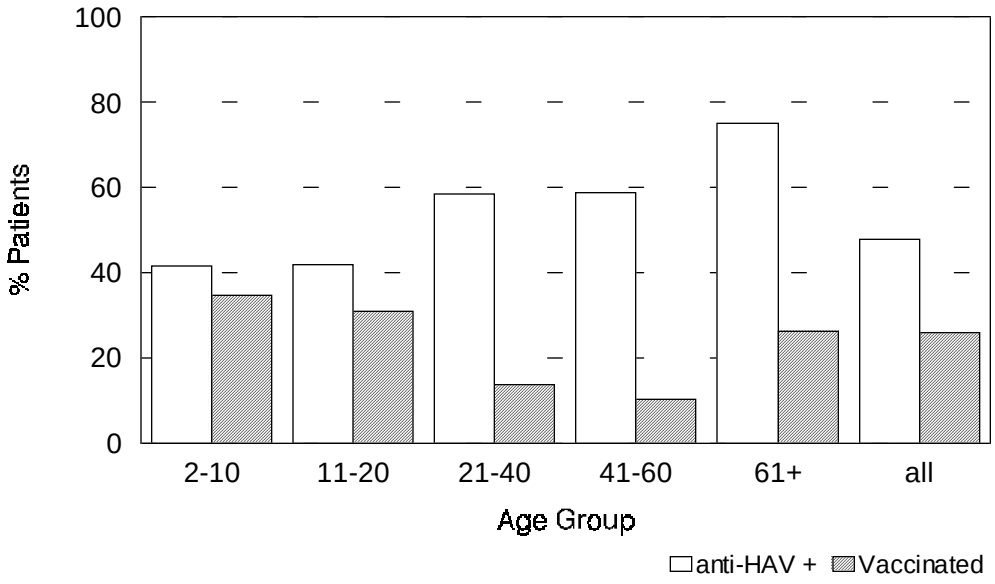
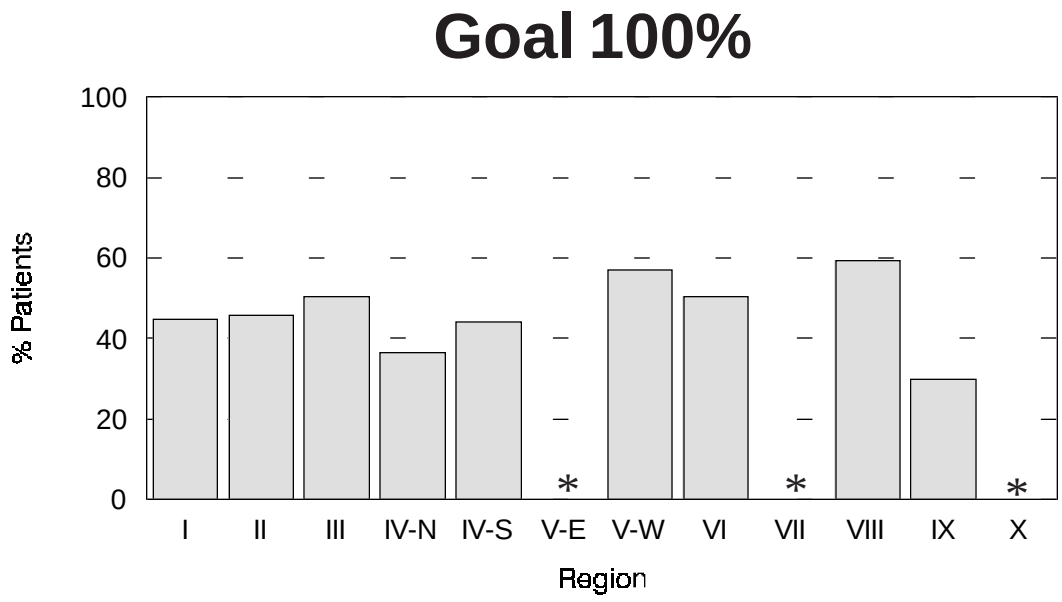


Figure 2. Regional* distribution of natural and acquired immunity to hepatitis A virus among persons with hemophilia.



*See map (p. 19) for regional designations.

* not started UDC

Figure 3. **Prevalence of hepatitis A virus and reported vaccination status among persons with von Willebrand disease.**

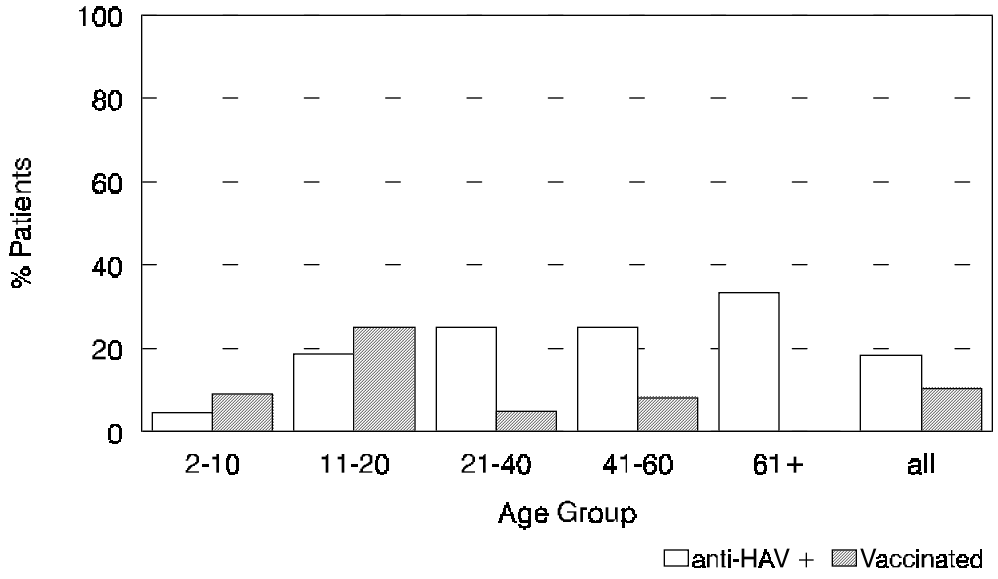


Figure 4. **Prevalence of hepatitis B virus exposure and reported vaccination status among persons with hemophilia.**

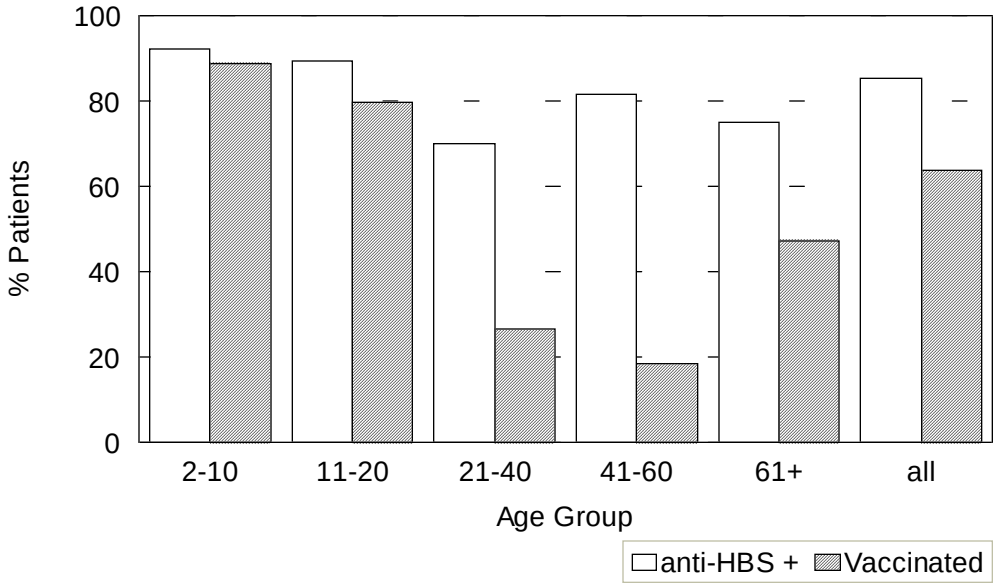
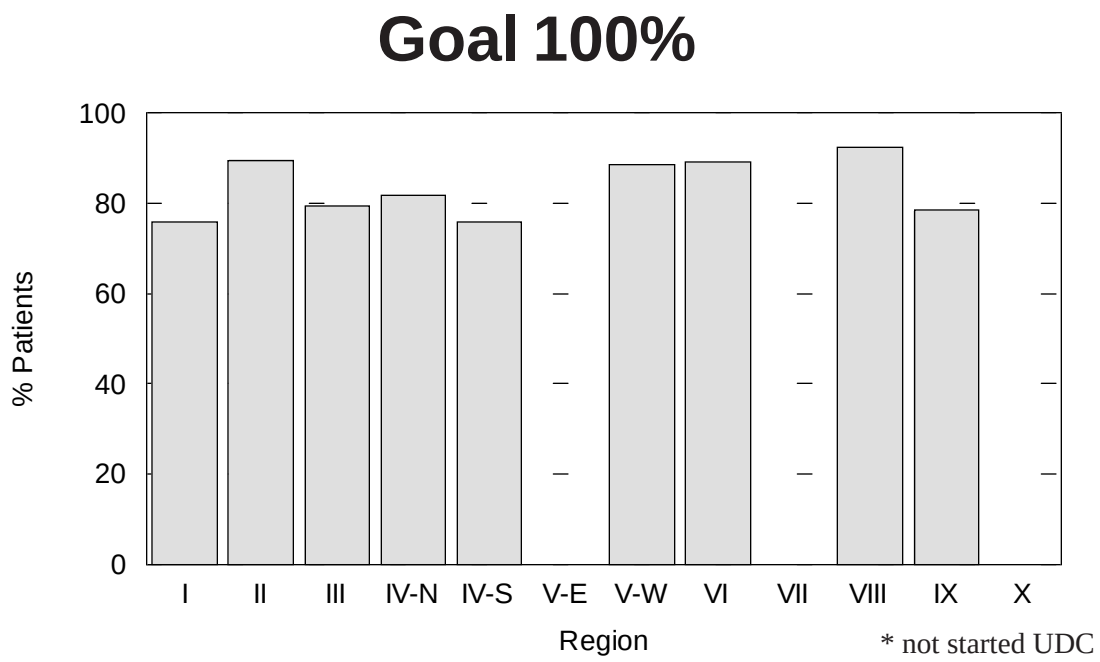


Figure 5. **Regional* distribution of natural and acquired immunity to hepatitis B virus among persons with hemophilia.**



*See map (p. 19) for regional designations.

Figure 6. **Prevalence of hepatitis B virus exposure and reported vaccination status among persons with von Willebrand disease.**

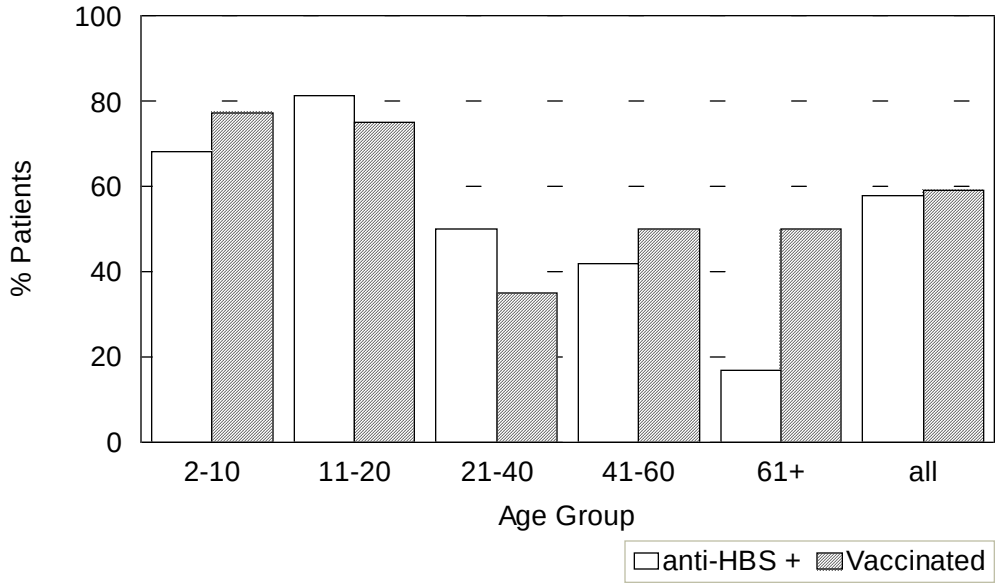


Figure 7. Prevalence of hepatitis C virus infection among persons with bleeding disorders.

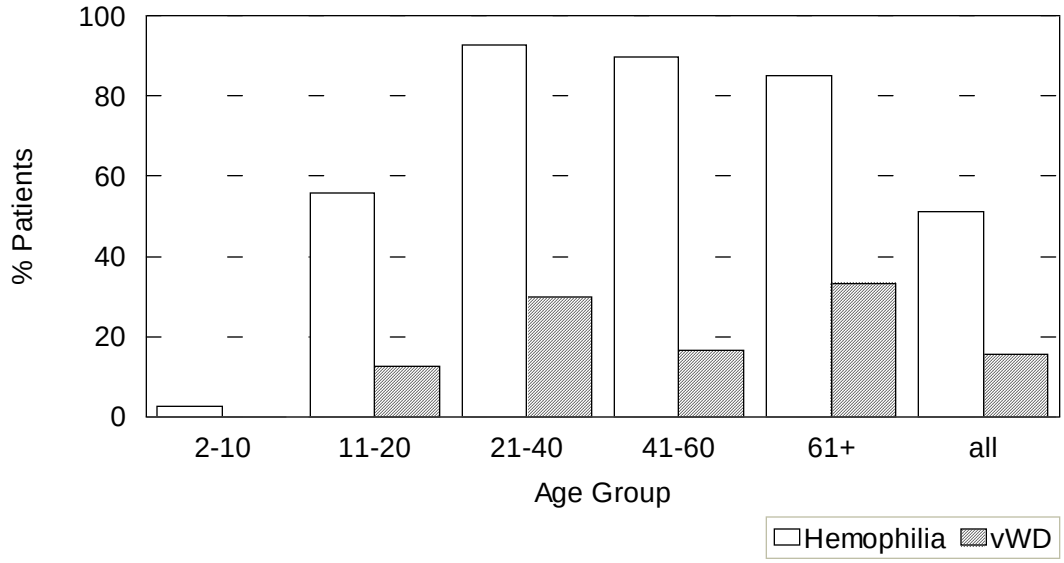


Figure 8. Prevalence of human immunodeficiency virus (HIV) infection among persons with hemophilia.

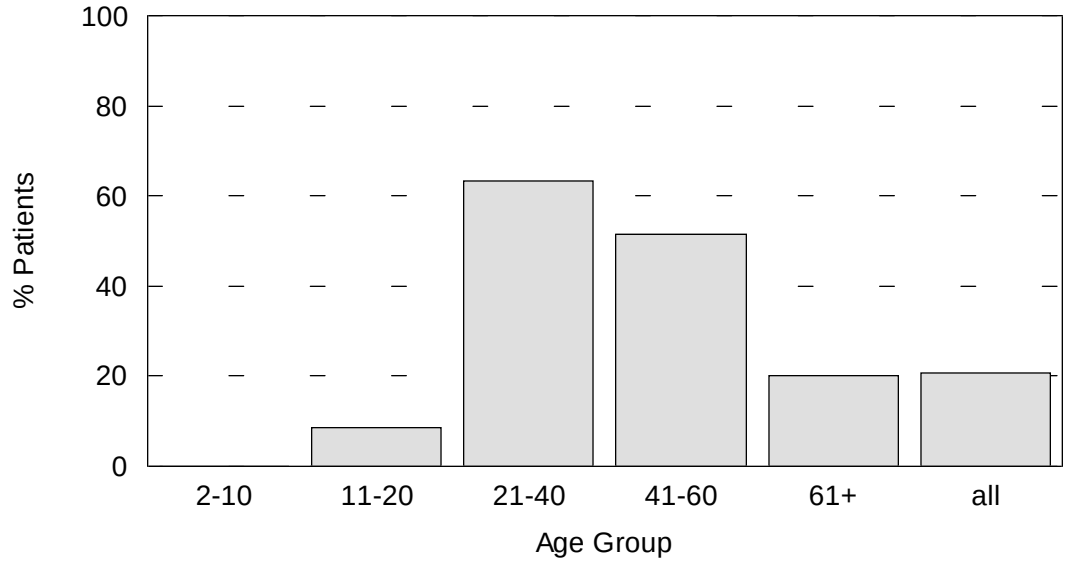


Table 7. Joint complications among persons enrolled in UDC.

	Hemophilia						vWD			
	Mild		Moderate		Severe		Type 1 & 2		Type 3	
	N	%	N	%	N	%	N	%	N	%
Target Joint*	14	10.2	63	32.8	264	52.5	1	1.6	6	28.6
Invasive Procedure	3	2.2	13	6.8	53	10.5	3	4.7	2	9.5
Joint Infection	2	1.5	4	2.1	13	2.6	0	-	0	-
Used Cane	20	14.7	50	26.0	150	29.8	2	3.3	1	4.8
Used Wheelchair	3	2.2	18	9.4	64	12.7	2	3.1	1	4.8
Any Activity Restriction	17	12.4	62	32.3	207	41.1	5	7.8	4	19.0

*Please see Technical Notes (p.16) for the definition of a target joint.

Table 8. Joint limitations* among persons enrolled in UDC.

	Hemophilia			vWD	
	Mild	Moderate	Severe	Type 1 & 2	Type 3
Number of patients	129	179	436	57	21
Mean indicator value	57.2	86.9	163.2	47.2	54.0
Standard deviation	107.1	158.1	229.6	102.8	129.8

*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 hyper-extension of the knee or elbow is not 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 57.2 degrees less than normal range of motion across ten joints.

Table 9. Causes of death among all persons with bleeding disorders who died in 1997.

	Hemophilia A		Hemophilia B		vWD	
Causes*	N	%	N	%	N	%
Hemophilia/vWD-related	15	11.2	5	16.1	1	8.3
HIV-related	73	54.5	9	29.0	0	-
Liver disease-related	23	17.2	6	19.4	1	8.3
Suicide	2	1.4	0	-	0	-
Other	17	12.7	7	22.6	8	66.7
Unknown	4	3.0	4	12.9	2	16.7
Totals	134		31		12	

*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 all persons with bleeding disorders who died in 1997.

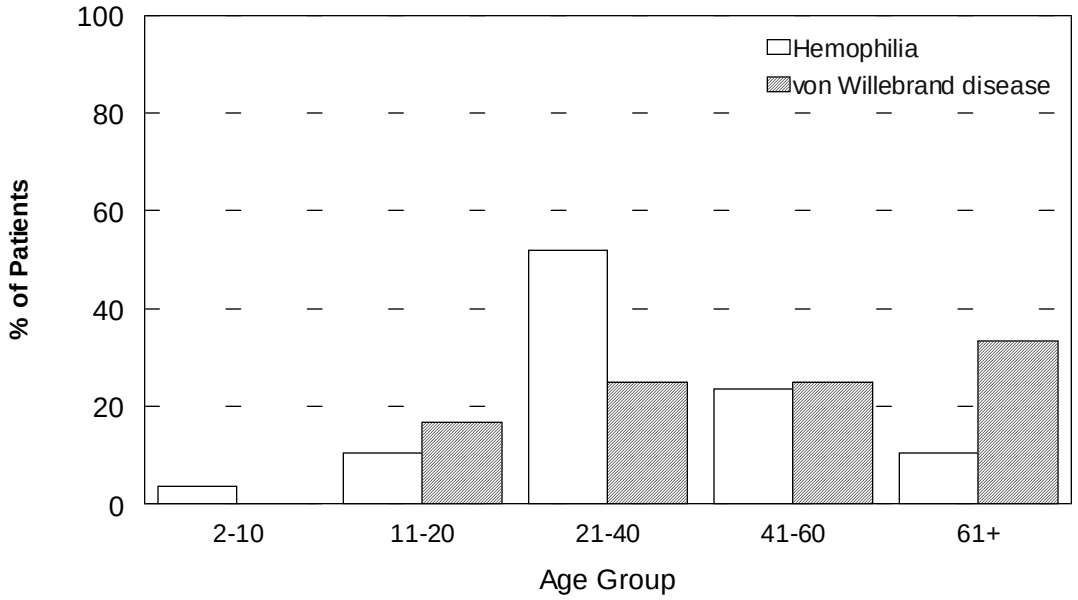
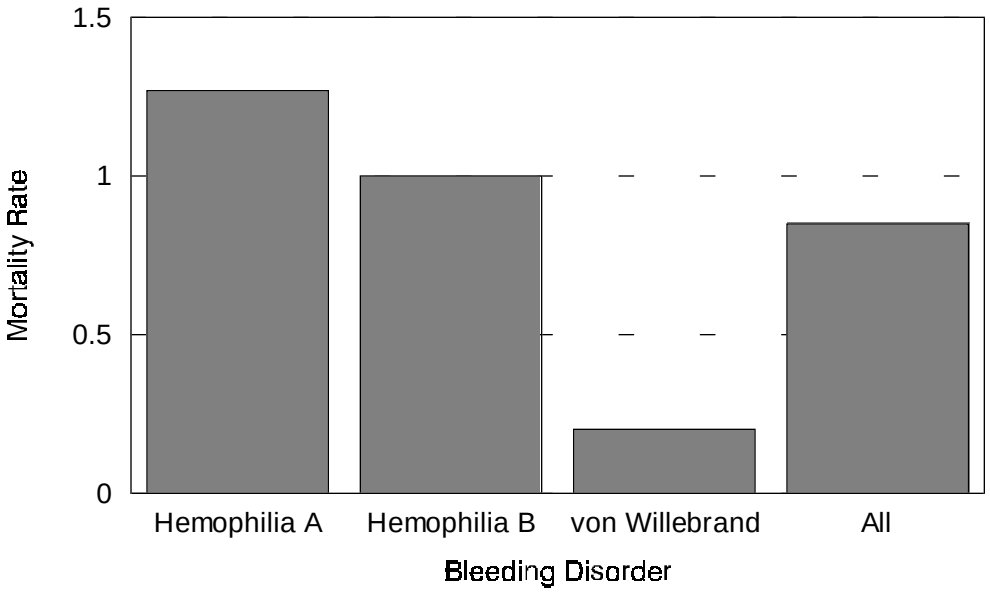


Figure 10. Disease-specific mortality rates* based on all persons with bleeding disorders who died in 1997.



*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 UDC Mortality Forms at the end of 1997 and the denominator is the number of active patients in each disease group followed in 1997 by HTCs as reported in the 1997 CDC Hemophilia Data Set (HDS).

NOTE: This is a crude mortality rate that is not adjusted for differences that may exist between the 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.

A section on joint disease collects data on 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 lifetime 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 6 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.

Acknowledgments

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
Vermont Regional Hemophilia Center
Burlington, VT

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
Albany Medical College
Albany, 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
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
Children's Hospital of Richland Memorial
Columbia, SC
Vanderbilt University Medical Center
Nashville, TN

Region IV-S *Crystal D. Watson, B.S.W.*
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
Emory University Hemophilia Program Office
Atlanta, GA

Region V-W *Mary Anne Schall, R.N., M.S.*
Northwestern University
Chicago, IL
Cook County Hospital - Adult
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
American Red Cross - Badger Chapter
Madison, WI
Rush Children's Hospital
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 Center
Houston, TX
Oklahoma Comprehensive Hemophilia Treatment Center, Oklahoma City, OK
South Texas Comprehensive Hemophilia Center, San Antonio, TX

Region VIII *Mary Lou Damiano, R.N., M.Ed.*
Mountain States Regional Hemophilia Center
Denver, CO
Ted R. Montoya Hemophilia Center
Albuquerque, NM
Mountain States Regional Hemophilia Center
Tucson, AZ

Region IX *Judith Baker, M.H.S.A.*
Children's Hospital of Los Angeles
Los Angeles, CA
University of California at Davis
Sacramento, CA
Children's Hospital Oakland
Oakland, CA
Hemophilia and Thrombosis Center of Nevada
Las Vegas, NV
Guam Comprehensive Hemophilia Care Program, Agana, GU

Hemophilia Treatment Center Regions