UDC
The Universal Data Collection Program
December 2003/Vol.5/No.1

# Report on the Universal Data Collection Program

*Special report summarizing data on females with von Willebrand disease*

Includes data collected from May 1998 through December 2002


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The *Report on the Universal Data Collection Program* is published by the Division of Hereditary Blood Disorders, National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention (CDC), Atlanta, Georgia 30333. All data are provisional.

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The *Report on the Universal Data Collection Program* is accessible via internet at http://www.cdc.gov/ncbddd/hbd/surveillance.htm Confidential information, referrals, and educational material on hemophilia and other bleeding disorders are also available by calling the National Hemophilia Foundatation's information line, HANDI, at 800-42-HANDI.

# Contents

Commentary ..... 3

**Tables**

Table 1. Disease severity among females with VWD ..... 8
Table 2. Demographic characteristics of females with VWD ..... 10
Table 3. Sources of health care reimbursement listed by females withVWD ..... 11
Table 4. Bleeding episodes among females with VWD ..... 11
Table 5. Age at diagnosis, first bleeding episode, and first HTC visit among females with VWD ..... 12
Table 6. Bleeding history among females with VWD ..... 12
Table 7. Joint complications among females with VWD ..... 13
Table 8. Treatment products currently used by females with VWD ..... 13
Table 9. Prevalence of HIV by age group among females with VWD ..... 14

**Figures**

Figure 1. Number of years of follow-up for females with VWD ..... 8
Figure 2. UDC participation and refusal rates among females with VWD through 2002 ..... 9
Figure 3. Visits by UDC female VWD patients through 2002 ..... 9
Figure 4. Prevalence of natural or acquired immunity to hepatitis A virus by age group among females with VWD ..... 14
Figure 5. Regional distribution of natural or acquired immunity to hepatitis A virus among females with VWD ..... 15
Figure 6. Prevalence of natural or acquired immunity to hepatitis B virus by age group among females with VWD ..... 15
Figure 7. Regional distribution of natural or acquired immunity to hepatitis B virus among females with VWD ..... 16
Figure 8. Prevalence of hepatitis C virus infection by age group among females with VWD ..... 16
Figure 9. Prevalence of hepatitis C infection by region among females with VWD ..... 17
Figure 10. Prevalence of natural or acquired immunity to hepatitis A virus by region among hepatitis C-infected females with VWD ..... 17

Technical Notes ..... 18
Acknowledgements ..... 20
Hemophilia Treatment Center Regional Map ..... 24

# Commentary

The two most common congenital bleeding disorders are von Willebrand disease (VWD) and hemophilia. VWD is caused by the defective synthesis or function of a protein, von Willebrand factor that 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 have the disease. Thus, almost all of the approximately 17,000 people 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 people 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 people with bleeding disorders. Since 1986, the Centers for Disease Control and Prevention (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 people with bleeding disorders and (2) to collect a uniform set of clinical outcomes information that can be used to monitor the occurrence of and potential risk factors for infectious diseases and joint complications.

People 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 is collected by HTC staff each year during each 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 UDC 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. In this volume, we focus on females with von Willebrand disease because of previous requests and ongoing interest in this special population. The next volume will contain data on all UDC patients through December 2002.

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 18.

**Highlights**

This issue of the UDC Surveillance Report focuses on women with von Willebrand disease (VWD) who have been enrolled in UDC. Following are some highlights taken from the tables that follow.

- During the period from May 1998 to December 2002, 1,400 women with VWD were enrolled in the UDC project, nearly three-fourths of whom have Type 1, the mildest form of the disorder (Table 1). The large proportion of women with unknown VWD type reflects, in many cases, the lack of availability of the complex testing capability required for the determination of VWD type in most laboratories throughout the country.

- For all three VWD types, about 50% of women receiving care in the treatment centers are under 21 years of age (Table 2). A possible reason for this may be that women experience the onset of menstruation during these years and menorrhagia (heavy menstrual bleeding) prompts many women with VWD to seek medical attention. As a result of CDC research, the American College of Obstetricians and Gynecologists made recommendations to screen women with menorrhagia for VWD.

- Women with type 1, 2 and 3 VWD reported on average 3.4, 3.5 and 5.9 episodes of bleeding during the previous 6-month period, respectively (Table 4). Most of the bleeds categorized as "Other" occur in the oral mucosa (gums) and the skin (easy bruising). Women with type 3 VWD are much more likely to experience bleeding into a joint than are women with either of the milder types.

- The median ages at which women receiving care in HTCs were diagnosed with VWD were 1, 7, and 13 years for type 3, type 2 and type 1 VWD, respectively (Table 5). The diagnosis of VWD in women may be delayed for a variety of reasons including lack of referral for testing, improper patient preparation for testing, and difficulties inherent in the proper implementation and interpretation of the available tests. For example, in a CDC survey of 75 women receiving care for VWD in treatment centers across the U.S., the average length of time for the diagnosis after the onset of symptoms was 16 years.

- The most common initial bleeding site for all three VWD types is the oral mucosa followed closely by the nasal mucosa (Table 6). Menorrhagia is a very common site for the first (abnormal or unusual?) bleed among women with type 1 VWD. The majority of women with either type 2 or type 3 VWD have received some form of blood product to treat a bleed during their lifetime.

- The prevalence of immunity to hepatitis A is less than 40% overall for women with VWD (Figure 4). Women with VWD are at risk for receiving blood and plasma-derived clotting factor products that have been known to transmit hepatitis A. For this reason, susceptible women with VWD should consider immunization against hepatitis A.

- The prevalence of immunity to hepatitis B is about 80% for women with VWD under 21 years of age (Figure 6). However, immunity levels decline among older women and reach a low of about 40% for women 61 years and over. Women with VWD are at risk for receiving blood and plasma-derived clotting factor products that have been known to transmit hepatitis B. Susceptible women with VWD should consider immunization against hepatitis B.

- The prevalence of hepatitis C among women with VWD is highest among women 21 years of age and older, just as it is in the general population (Figure 8). However, the rates of infection are 3.5 to 5 times higher for women with VWD. The elevated rates are most likely due to treatment with blood and plasma-derived clotting factor products prior to the initiation of donor screening and the availability of virally inactivated clotting factor.

- The prevalence of immunity to hepatitis A among women with VWD who are infected with hepatitis C is quite variable throughout the country and overall is less than 60% (Figure 10). Infection with hepatitis A can cause more serious illness among persons

who are hepatitis C infected. Women with VWD are at risk for receiving blood and plasma-derived clotting factor products that have been known to transmit hepatitis A. For this reason, susceptible women with VWD who are also hepatitis C infected should consider immunization against hepatitis A.

## Suggested Reading


Centers for Disease Control and Prevention. 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.

Centers for Disease Control and Prevention. Blood safety monitoring among persons with bleeding disorders — United States, May 1998—June 2002. MMWR 2003; 51(51);1152-1154

Dilley A, Crudder S. von Willebrand disease in women: the need for recognition and understanding. J Womens Health Gend Based Med 1999;8(4):443-445.


*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)

Information packet on von Willebrand disease.

**Table 1. Disease severity among females with VWD**

| vWD Type | Number | (%) |
|---|---|---|
| Type 1 | 1015 | (72.5) |
| Type 2a | 95 | (6.8) |
| Type 2b | 57 | (4.1) |
| Type 2m | 8 | (0.6) |
| Type 2n | 12 | (0.9) |
| Type 2 other | 9 | (0.6) |
| Type 3 | 86 | (6.1) |
| Unknown | 118 | (8.4) |
| Total | 1400 | |

*All subsequent data presented in this report exclude females with unknown type VWD from the analysis.

**Figure 1. Number of years of follow-up for females with VWD**

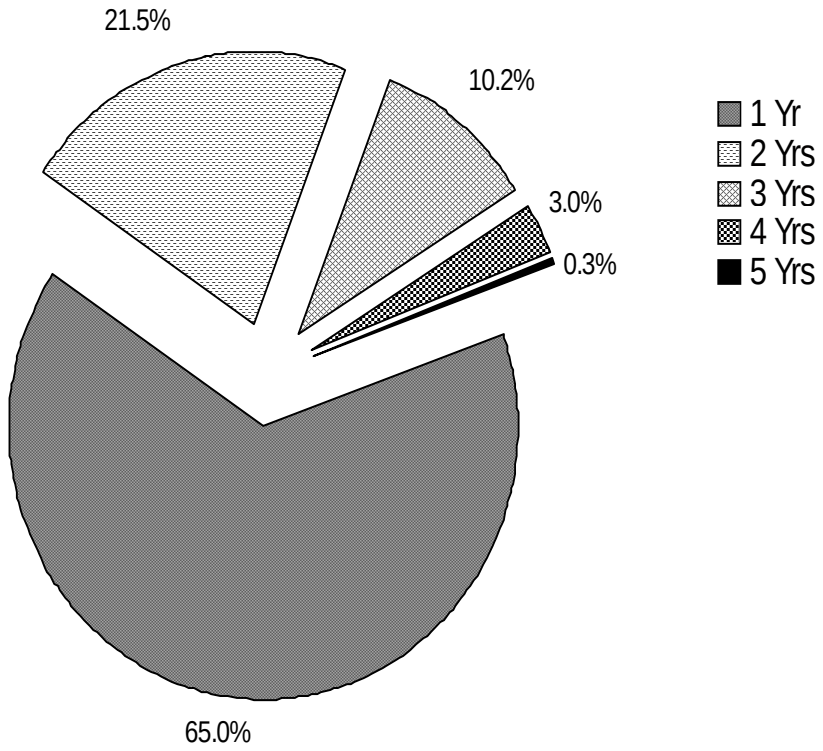


**Figure 2. UDC participation and refusal rates among females with VWD through 2002**

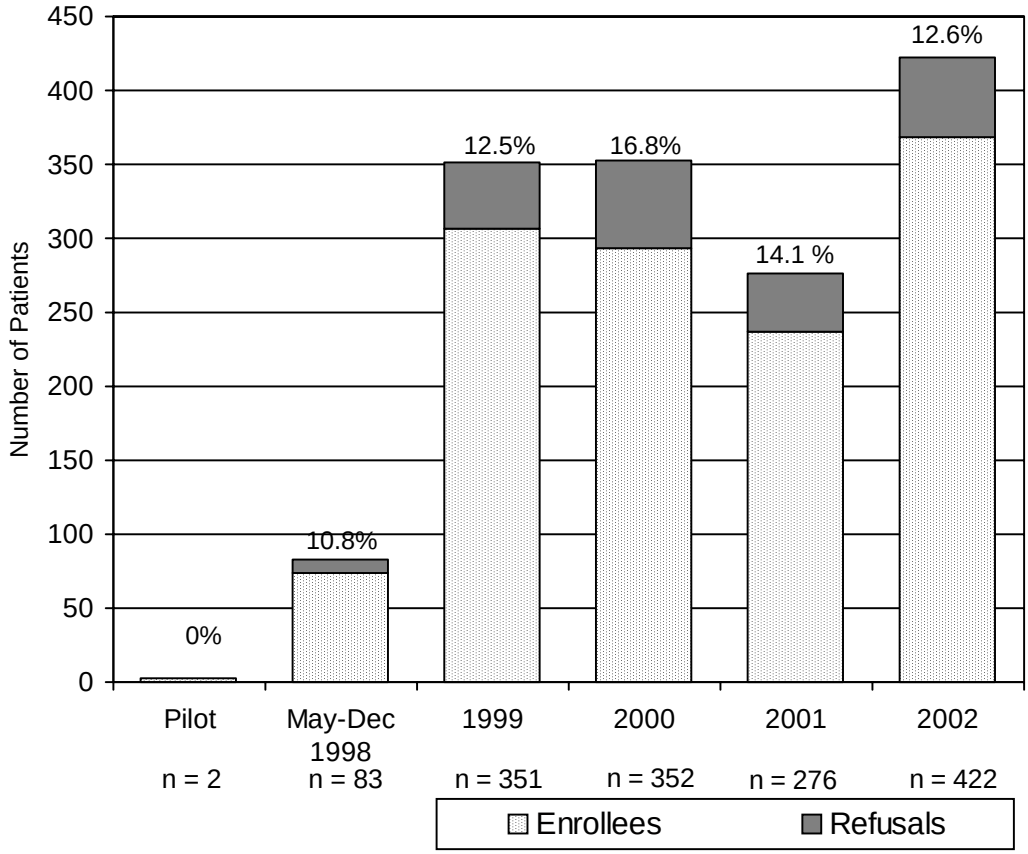
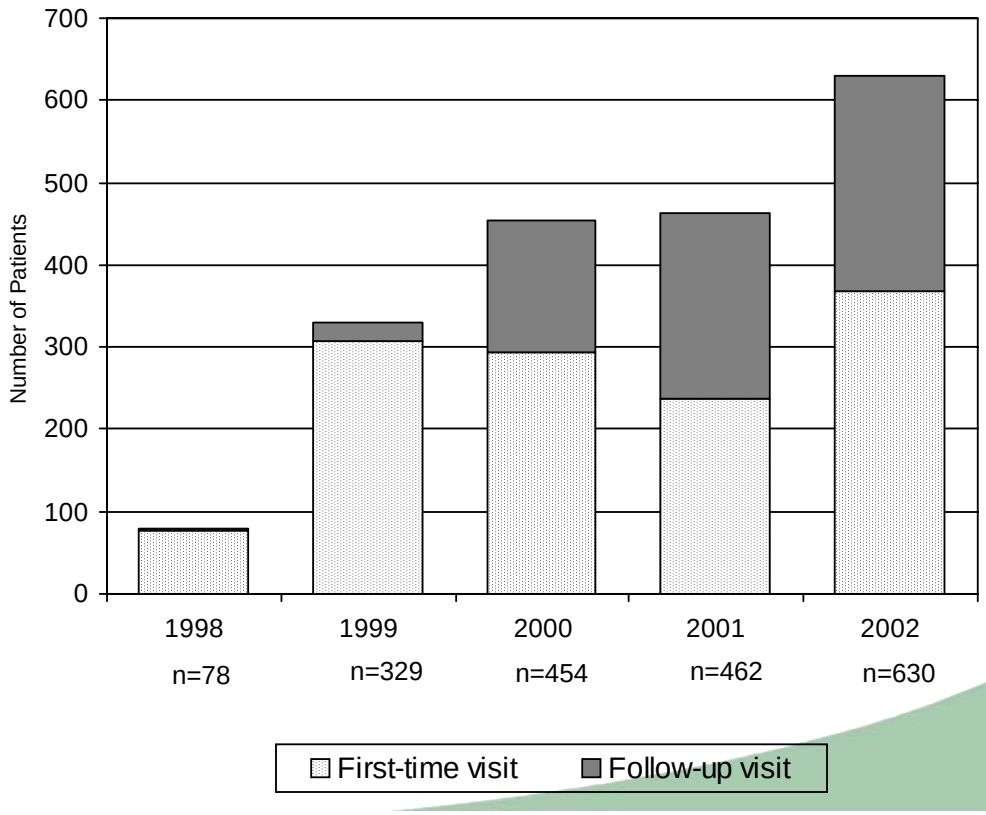



**Figure 3. Visits by UDC female VWD patients through 2002**



## Table 2. Demographic characteristics of females with vWD

| | Type 1 (n =1015) | | Type 2 (n=181) | | Type 3 (n = 86) | |
|---|---|---|---|---|---|---|
| **Characteristic** | **Number** | **Percent** | **Number** | **Percent** | **Number** | **Percent** |
| **Age Group (yrs)** | | | | | | |
| 2-10 | 132 | 13.0 | 29 | 16.0 | 20 | 28.3 |
| 11-20 | 371 | 36.6 | 49 | 27.1 | 24 | 27.9 |
| 21-40 | 249 | 24.5 | 54 | 29.8 | 26 | 30.2 |
| 41-60 | 204 | 20.1 | 34 | 18.8 | 13 | 15.1 |
| >60 | 59 | 5.8 | 15 | 8.3 | 3 | 3.5 |
| **Race/Ethnicity** | | | | | | |
| White | 778 | 77.6 | 133 | 73.5 | 71 | 82.6 |
| African American | 53 | 12.5 | 11 | 11.2 | 3 | 5.5 |
| Hispanic | 122 | 12.0 | 20 | 11.0 | 5 | 5.8 |
| Asian/Pacific Islander | 20 | 2.0 | 9 | 5.0 | 3 | 3.5 |
| Native American | 8 | 0.8 | 1 | 0.6 | 0 | 0.0 |
| Other | 24 | 2.4 | 7 | 3.9 | 4 | 4.7 |
| **Education** | | | | | | |
| Pre-elementary | 59 | 5.8 | 15 | 8.3 | 12 | 14.0 |
| Primary/Secondary | 432 | 42.6 | 66 | 36.4 | 32 | 37.2 |
| High school graduate | 238 | 23.4 | 50 | 27.6 | 18 | 20.9 |
| Technical school | 49 | 4.8 | 9 | 5.0 | 4 | 4.6 |
| College degree | 124 | 12.2 | 23 | 12.7 | 9 | 10.5 |
| Advanced degree | 36 | 3.6 | 9 | 5.0 | 6 | 7.0 |
| Other | 77 | 7.6 | 9 | 5.0 | 5 | 5.8 |
| **Employment** | | | | | | |
| Full time | 238 | 23.4 | 40 | 22.1 | 15 | 17.4 |
| Part time | 103 | 10.2 | 26 | 14.4 | 5 | 5.8 |
| Not employed | 674 | 66.4 | 115 | 63.5 | 66 | 76.8 |
| Student | 483 | 71.6* | 76 | 66.1 | 44 | 66.7 |
| Homemaker | 84 | 12.5 | 16 | 14.0 | 7 | 10.6 |
| Able, no job | 22 | 3.3 | 5 | 4.3 | 4 | 6.1 |
| Disabled | 37 | 5.5 | 5 | 4.3 | 9 | 13.6 |
| Retired | 39 | 5.8 | 11 | 9.6 | 1 | 1.5 |
| Other | 9 | 1.3 | 2 | 1.7 | 1 | 1.5 |

*For not employed categories (Student, Homemaker, etc.) percentages are number in category out of number not employed.

## Table 3. Sources* of health care reimbursement listed by females with VWD

| | Type 1 (n = 1015) | | Type 2 (n = 181) | | Type 3 (n = 86) | |
|---|---|---|---|---|---|---|
| **Reinbursement source** | **Number** | **Percent** | **Number** | **Percent** | **Number** | **Percent** |
| Commercial insurance | 237 | 23.3 | 47 | 26.0 | 21 | 24.4 |
| Commercial HMO | 284 | 28.0 | 48 | 26.5 | 12 | 14.0 |
| Commercial PPO | 197 | 19.4 | 39 | 21.6 | 22 | 25.6 |
| Medicare | 56 | 5.5 | 10 | 5.5 | 6 | 7.0 |
| Medicare HMO | 11 | 1.1 | 2 | 1.1 | 1 | 1.2 |
| Medicaid | 114 | 11.2 | 16 | 8.8 | 19 | 22.1 |
| Medicaid HMO | 66 | 6.5 | 9 | 5.0 | 6 | 7.0 |
| CHAMPUS | 14 | 1.4 | 1 | 0.6 | 2 | 2.3 |
| State high risk plan | 9 | 0.9 | 4 | 2.2 | 5 | 5.8 |
| Other | 116 | 11.4 | 24 | 13.3 | 9 | 10.5 |
| Uninsured | 40 | 3.9 | 7 | 3.9 | 4 | 4.7 |

*Some people may have listed more than one source of reimbursement.
HMO = health maintenance organization; PPO = preferred provider organization.

## Table 4. Bleeding episodes* among females with VWD

| | Type 1 mean (±) | Type 2 mean (±) | Type 3 mean (±) |
|---|---|---|---|
| **Bleeding site** | | | |
| Joint | 0.1 (±0.9) | 0.2 (±1.8) | 1.3 (±2.5) |
| Muscle | 0.1 (±1.3) | 0.1 (±0.4) | 0.5 (±1.5) |
| Other | 3.2 (±9.6) | 3.3 (±14.1) | 4.2 (±8.4) |
| **All sites** | **3.4 (±9.8)** | **3.5 (±14.2)** | **5.9 (±9.3)** |

*Values are mean and standard deviation number of bleeding episodes experienced during the 6-month period preceding the UDC visit.

## Table 5. Age at diagnosis, first bleeding episode, and first HTC visit among females with VWD

| | Type1 | Type 2 | Type 3 |
|---|---|---|---|
| **Age diagnosed** | **n = 988** | **n = 179** | **n = 83** |
| median (range) | 13 (0-73) | 7 (0-73) | 1 (0-71) |
| **Age at first bleed** | **n = 714** | **n = 138** | **n = 73** |
| median (range) | 10 (0-57) | 4 (0-65) | 1 (0-59) |
| **Age first HTC visit** | **n = 992** | **n = 175** | **n = 81** |
| median (range) | 14 (0- 73) | 11 (0-75) | 4 (0-73) |

## Table 6. Bleeding history among females with VWD

| | Type 1 | | Type 2 | | Type3 | |
|---|---|---|---|---|---|---|
| | **n** | **(%)** | **n** | **(%)** | **n** | **(%)** |
| **Females who have ever bled** | **845** | **(83.3)** | **158** | **(87.3)** | **84** | **(97.7)** |
| **Origin of first bleed*** | | | | | | |
| Head | 15 | (17.8) | 4 | (2.5) | 6 | (7.1) |
| Muscle | 2 | (0.2) | 6 | (3.8) | 3 | (3.6) |
| Joint | 26 | (3.1) | 1 | (0.6) | 3 | (3.6) |
| Oral mucosa | 236 | (27.9) | 60 | (38.0) | 31 | (36.9) |
| Soft tissue | 36 | (4.3) | 6 | (3.8) | 5 | (6.0) |
| Pregancancy | 21 | (2.5) | 4 | (2.5) | 0 | -- |
| Menorrhagia | 193 | (22.8) | 18 | (11.4) | 0 | -- |
| Nose bleed | 175 | (20.7) | 37 | (23.4) | 17 | (20.2) |
| Other | 96 | (11.4) | 16 | (10.1) | 12 | (14.3) |
| Unknown | 39 | (4.6) | 5 | (3.2) | 6 | (7.1) |
| Missing data | 8 | (0.9) | 2 | (1.3) | 1 | (1.2) |
| **Received blood products** | 350 | (34.5) | 118 | (65.2) | 78 | (90.7) |
| **Family history** | 678 | (66.8) | 142 | (78.5) | 49 | (57.0) |
| **Total** | **1015** | | **181** | | **86** | |

*Percent is number out of total patients who have ever had a bleeding episode.
** Blood products include, whole blood, blood fraction or component(e.g., platetes, cryoprecipitate, fresh frozen plasma), or factor concentrates

## Table 7. Joint complications among females with VWD

| | Type 1 n (%) | Type 2 n (%) | Type 3 n (%) |
|---|---|---|---|
| Target joint* | 15 (1.5) | 3 (1.7) | 14 (16.3) |
| Invasive procedure | 19 (1.9) | 1 (0.6) | 6 (7.0) |
| Joint infection | 16 (1.6) | 0 | 0 |
| Used cane | 68 (6.7) | 7 (3.9) | 8 (9.3) |
| Used wheelchair | 22 (2.2) | 2 (1.1) | 4 (4.7) |
| Any activity restriction | 99 (9.8) | 14 (7.7) | 25 (29.1) |
| **Total** | **1015** | **181** | **86** |

*Please see Technical Notes (page 17) for the definition of a target joint.

## Table 8. Treatment products currently used* by females with VWD

| | Type 1 n = 1015 | | Type 2 n = 181 | | Type 3 n = 86 | |
|---|---|---|---|---|---|---|
| Treatment product | Number | Percent | Number | Percent | Number | Percent |
| Recombinant factor | 3 | 0.3 | 0 | -- | 1 | 1.2 |
| Other human factor VIII | 103 | 10.1 | 65 | 35.9 | 67 | 77.9 |
| Cryoprecipitate of FFP | 12 | 1.2 | 1 | 0.6 | 2 | 2.3 |
| Desompressin | 512 | 50.4 | 52 | 28.7 | 1 | 1.1 |
| None used | 393 | 38.7 | 62 | 34.3 | 15 | 17.4 |

*Any use of the product(s) during the 12-month period preceding the most recent visit.
NOTE: Individuals may have used more than one type of treatment product.

**Table 9. Prevalence of HIV by age group among females with VWD**

| Age Group | Type 1 | | | Type 2 | | | Type 3 | | | Total |
|---|---|---|---|---|---|---|---|---|---|---|
| years | n | HIV+ | (%) | n | HIV+ | (%) | n | HIV + | (%) | |
| 2 -10 | 123 | 0 | -- | 27 | 0 | -- | 20 | 0 | -- | 170 |
| 11-20 | 347 | 1 | (0.3) | 48 | 0 | -- | 22 | 1 | (4.6) | 417 |
| 21-40 | 236 | 2 | (0.9) | 49 | 1 | (2.0) | 24 | 2 | (8.3) | 309 |
| 41-60 | 196 | 2 | (1.0) | 31 | 0 | -- | 13 | 0 | -- | 240 |
| >60 | 56 | 0 | -- | 14 | 0 | -- | 3 | 0 | -- | 73 |

**Figure 4. Prevalence of natural or acquired immunity to hepatitis A virus by age group among females withVWD**

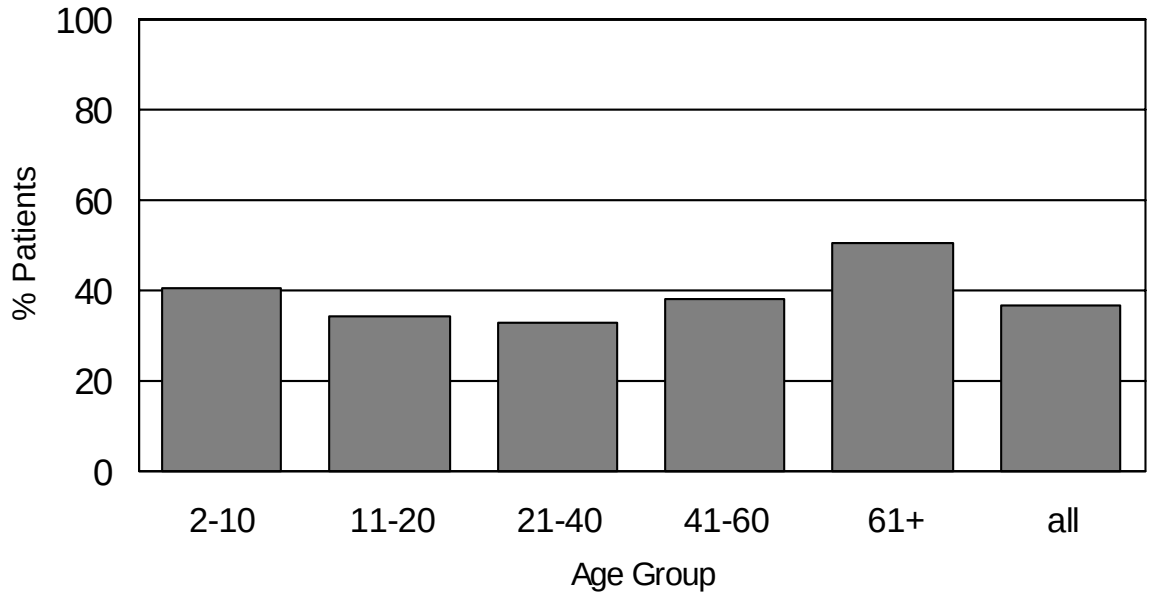


**Figure 5. Regional distribution of natural or acquired immunity to hepatitis A virus among females with VWD**

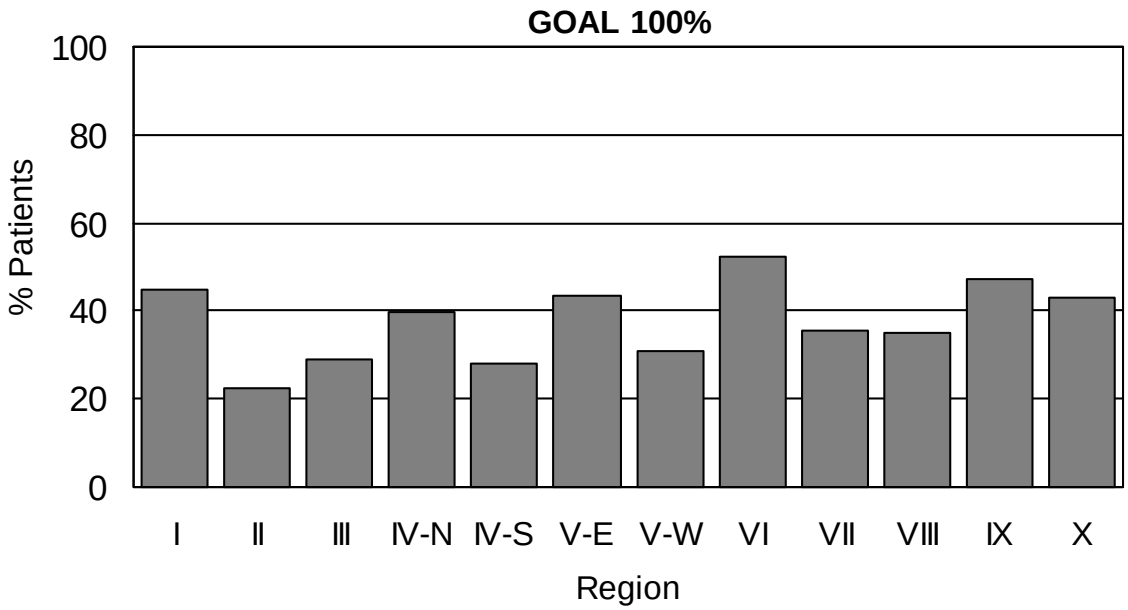



**Figure 6. Prevalence of natural or acquired immunity to hepatitis B virus by age group among females with VWD**

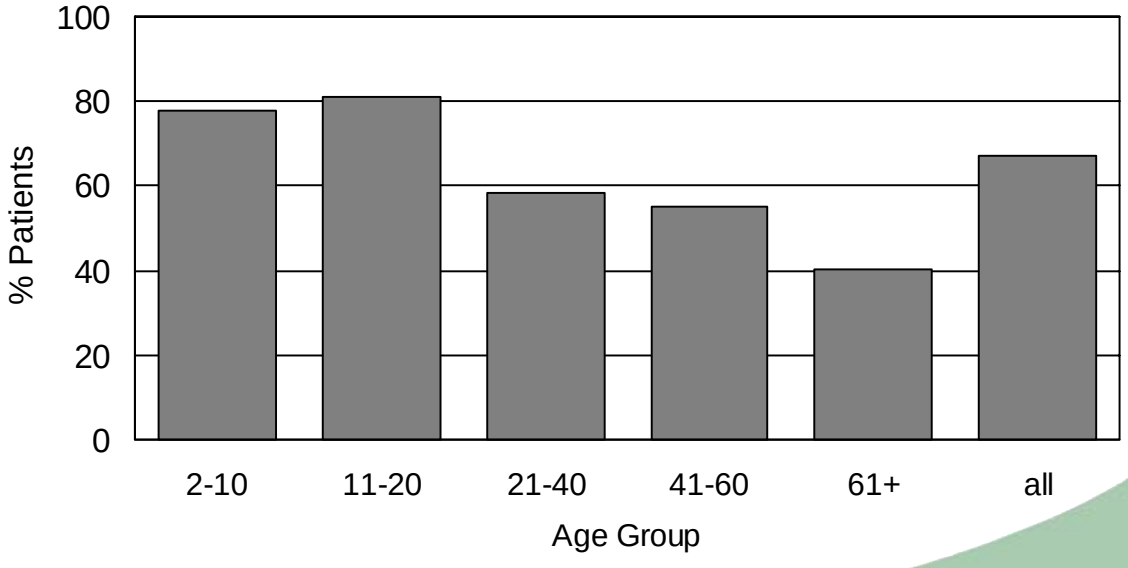


**Figure 7. Regional distribution of natural or acquired immunity to hepatitis B virus among females with VWD**

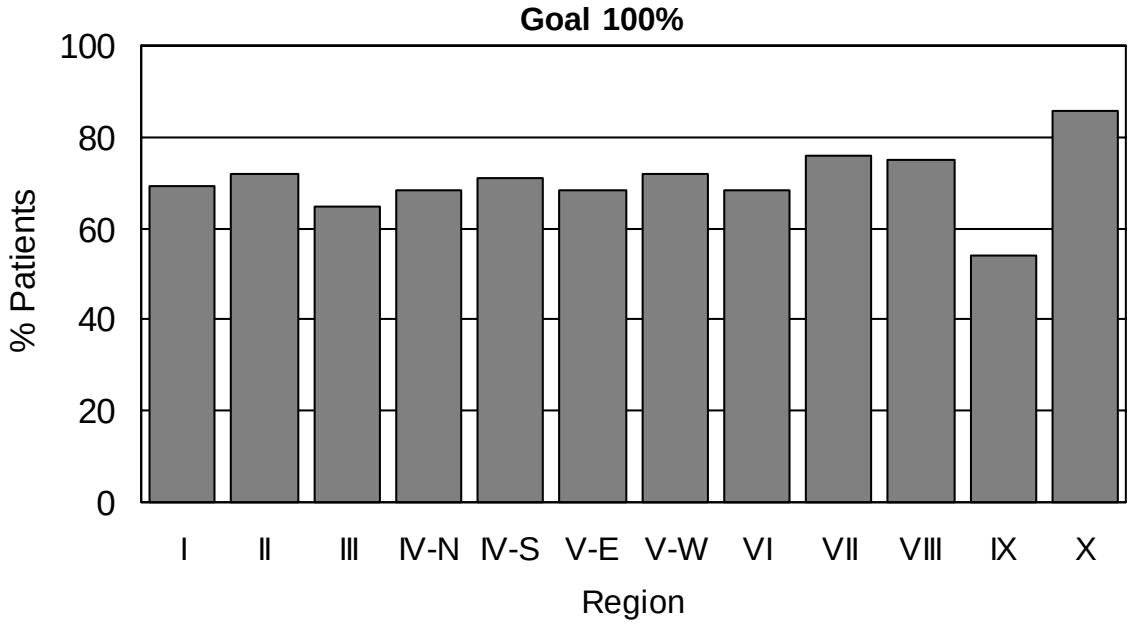



**Figure 8. Prevalence of hepatitis C virus infection by age group among females with VWD**

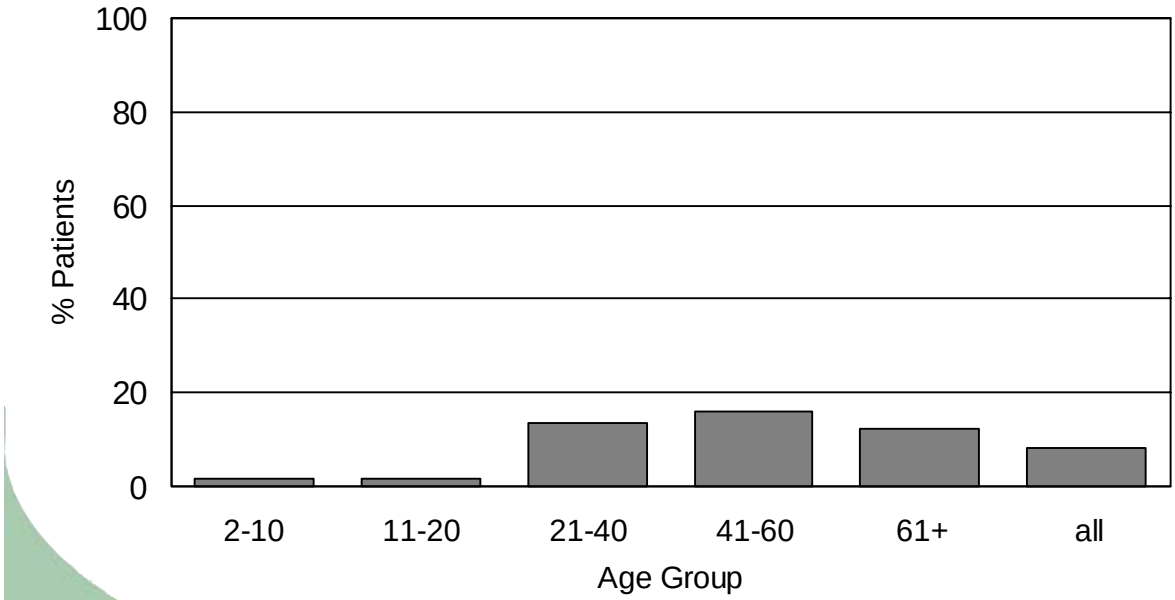


**Figure 9. Prevalence of hepatitis C infection by region among females with VWD**

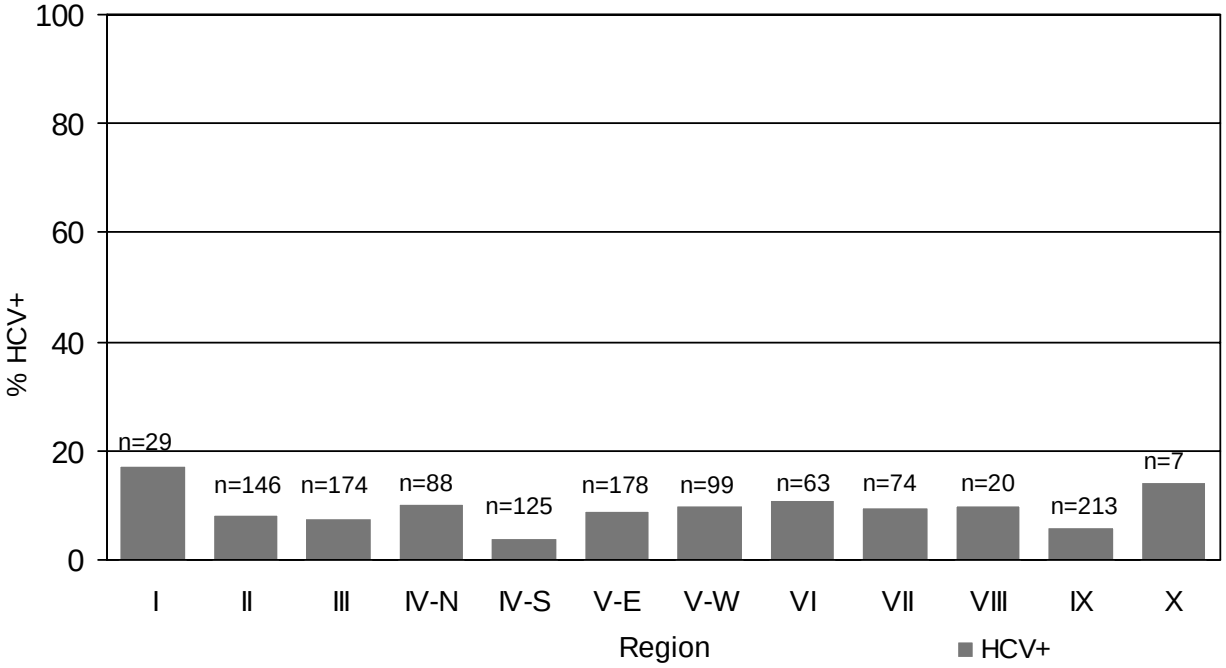
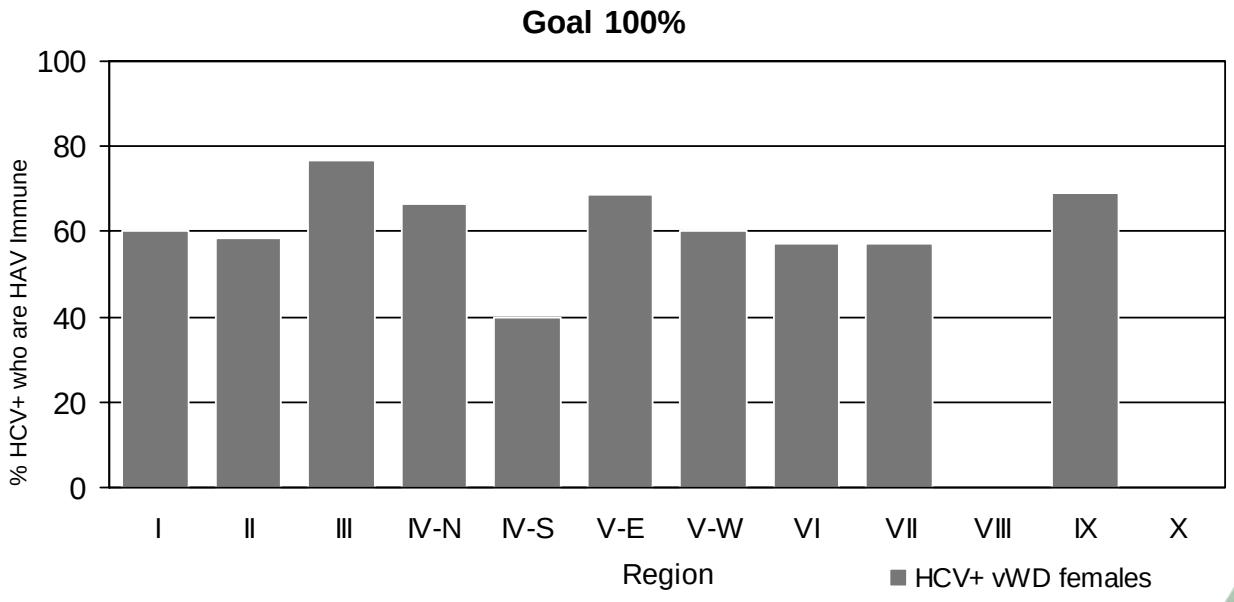



**Figure 10. Prevalence of natural or acquired immunity to hepatitis A virus by region among hepatitis C-infected females with VWD**



# 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) be 2 years of age 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 %; or (2) be 2 years of age 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 a 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 people who decline to participate. To protect patient confidentiality, all data sent to CDC do not contain personal 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; information collected on 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 might be 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 the type of treatment (episodic vs. prophylactic), presence and treatment of inhibitors, the number of bleeding episodes experienced (based on infusion logs or patient recall), the 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. People $\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.

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. Each 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 each 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 follows 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 that can be matched to the patient only by HTC staff.

**Mortality Reporting**

Deaths occurring among all HTC patients (regardless of whether they have been enrolled in UDC) are reported to CDC using a mortality form. Data collected include age at death, sex, race or ethnicity, type and severity of disease, 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 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.

# Acknowledgements

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**Region I**
*Ann Forsberg, M.A., M.P.H.*
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, MDChildren's Hospital of
Philadelphia Specialty
Center, Voorhees, NJ
Penn Comprehensive Hemophilia Program
Philadelphia, PA

**Region IV-N**
*Marney B. McCague and Sita Topalli*
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**
*Karen Droze, M.S.*
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

**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**
*Becky Dudley, L.C.S.W.*
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**
*Brenda Riske, M.S., M.B.A., M.P.A.*
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

**Region X**
*Robina Ingram-Rich, R.N., M.S., M.P.H.*
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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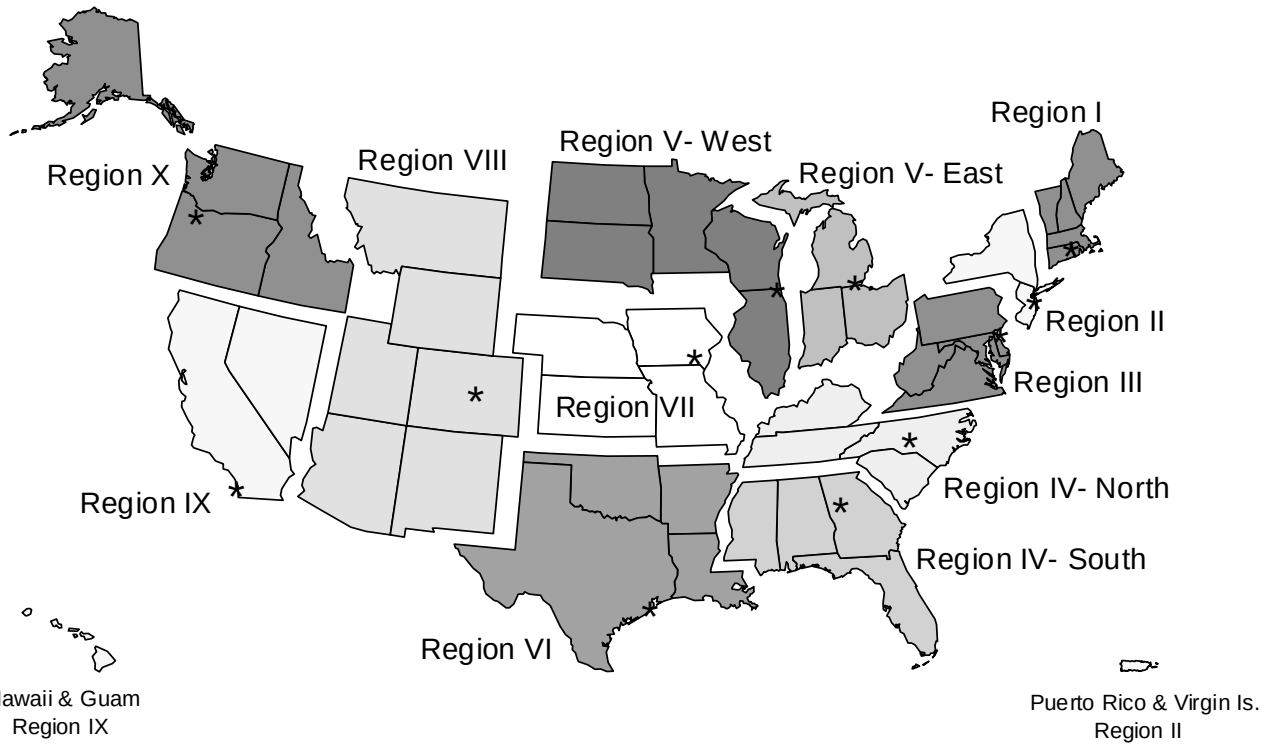
Tom Abshire, M.D.
Atlanta, GA
Randall Curtis, M.B.A
Berkeley, CA
Ann Forsberg, M.A., M.P.H.
Worcester, MA
Angela Forsyth, M.S., P.T.
Philadelphia, PA
Sue Geraghty, R.N., M.B.A.
Aurora, CO
Julie Hambleton, M.D.
San Francisco, CA
Marilyn Gradwoski, M.S.W.
Phoenix, AZ
W. Keith Hoots, M.D.
Houston, TX
Heather Huszti, Ph.D.
Oklahoma City, OK
Robert Janco, M.D.
Nashville, TN
Roshni Kulkarni, M.D.
East Lansing, MI
Margaret Wagner, R.N.
Newark, DE
Gilbert C, White, II, M.D.
Chapel Hill, NC

# Hemophilia Treatment Center Regions




*Location of regional core center.

**Department of Health and Human Services**
**Centers for Disease Control and Prevention**