

**UDC**  
**The Universal Data Collection Program**  
September 2004/Vol.6/No.2

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**Report on the Universal Data  
Collection Program**

Includes data collected from May 1998 through December 2003



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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 Foundation's information line, HANDI, at 800-42-HANDI.

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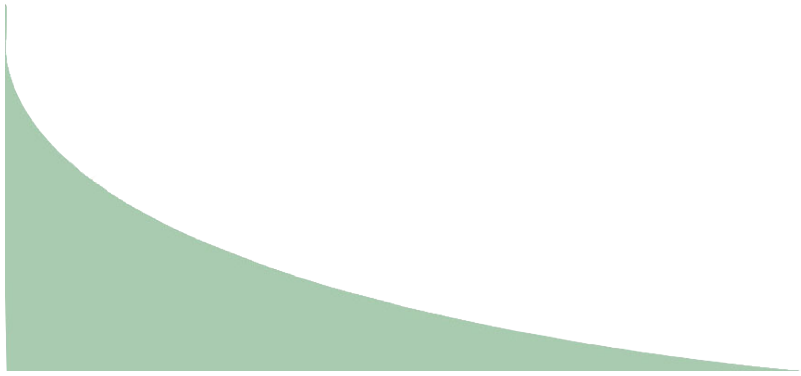
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## Commentary

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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 140 federally funded HTC's. 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 HTC's 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.

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 data collected from people who have been enrolled through December 2003.

Since May, 1998, 13,967 people with bleeding disorders have been enrolled. There have been 31,321 UDC visits. The overall national refusal rate is 7.8%.

Figures 1 and 2 show new enrollment in UDC. The decline of new enrollees who have either hemophilia or VWD represents the success of UDC in capturing more and more of the population over time.

Figures 3 and 4 show UDC visits over time and by region. UDC visits have increased over time.

Figures 5 and 6 show the refusal rates in UDC from May 1998 through December 2003 by year and region. Refusal rates have generally declined over time, the exceptions being a rise in the refusal rate among people with hemophilia from 8.2% in 1998 to 10.5% in 1999 and also among people with VWD whose refusal rate rose from 9.6% in 1999 to 11.2% in 2000. At all other intervals for both bleeding disorders, refusal rates have declined over time. The overall refusal rate is 7.5% for people with hemophilia and 8.7% for people with VWD. Refusal rates through December 2003 in regions I through IX remained below 15%, with a low of 2.8% in Region VIII among people with hemophilia to a high of 14.1% among people with VWD in Region VII.

In Region X refusal rates are unusually high due to low numbers of people enrolled in UDC.

Figure 7 shows the follow-up time for people enrolled in UDC. More than half of people enrolled in UDC have follow-up time of over 1 year.

Figure 8 shows the number of people who have a first-time visit compared to those who have a follow-up visit for each year through December 2003. The number of people who have a first time visit have gone down as a proportion of total visits and those with follow-up visits have increased over time.

The distribution of demographic characteristics (Table 1) and sources of healthcare reimbursement (Table 2) have remained consistent over the course of the study. About 50% of people with hemophilia are  $\leq 20$  years of age and nearly all are males. An ever greater proportion of people with VWD are  $\leq 20$  years old and this population is evenly divided among men and women. The population distribution by race and ethnicity is similar to that of the general population. With regard to healthcare reimbursement, about 60% of patients have some form of commercial insurance, about 30% have government sponsored coverage and the remainder have other types of insurance. Only about 3-4% of patients are uninsured.

As depicted in Table 3, one quarter of people with hemophilia have mild disease, 23.0% have moderate disease, and 51.9% have severe disease. 70.9% of people with VWD are classified as having Type 1, 11.1% as having Type 2, 7.3% as having Type 3, and 10.8% are classified as having other or unknown type of VWD.

Table 4 shows the average number of bleeds by disease severity and prophylaxis use among people with hemophilia and VWD. For people with moderate hemophilia, the reported bleeding frequency was similar for those who were using prophylaxis compared with those who received episodic care. On the other hand, people with severe disease on prophylaxis reported far fewer bleeds than those on episodic care. Among people with VWD, as expected, those with Type 3 VWD had the most bleeds. Bleeding was far more common in sites other than joints and muscles among people with VWD compared to those with hemophilia.

In Table 5, most people had no risk factors or symptoms associated with liver disease. 204 (28.9%) of the 709 people with hemophilia receiving any therapy for viral hepatitis had successful treatment of the disease. 1222 (11.5%) people with hemophilia had an intravenous access device (IVAD) in the year previous to their most recent visit. Of these, 137 (11.2%) had an IVAD associated infection.

Table 6 shows that the most common type of treatment used for all severity levels of hemophilia was episodic care. 10.8% of people with moderate disease used continuous prophylaxis and 8.0% of those with severe disease used intermittent prophylaxis. As expected, patients with severe disease were the most likely to be on continuous prophylaxis.

Prevalence of inhibitors (Table 7) is highest among people with severe hemophilia A. Inhibitors are much less common among people with hemophilia B.

The proportion of overall factor product use (Table 8) has remained consistent throughout the surveillance period. The majority of people use recombinant products.

In Figure 9, multiple factor product use in people with hemophilia using any product is between 5% and 10% for all age groups except those aged 2-5, where multiple product use is 3.8%.

Table 9 shows people with hemophilia on episodic care and intermittent prophylaxis are more likely to use multiple factor products than those who are on continuous prophylaxis. This may reflect the reluctance of those on continuous prophylaxis to change products.

People with mild hemophilia are more likely to use multiple factor products (10.5%) than people with moderate (5.3%) or severe (6.8%) disease. The overall prevalence of multiple factor product use among those using at least one factor product is 7.4% (Table 10).

Table 11 shows that in both people with Hemophilia A and B, those with high inhibitor titer are much more likely to use multiple factor products (32.9% and 44.4 % respectively) than those with low or negative inhibitor titers. This finding reflects the fact that people with inhibitors use other products to control bleeding episodes when their current product fails to do so.

Figure 10 illustrates that people with hemophilia A who have mild disease have a lower prevalence of intra-cranial hemorrhage (ICH) over time than those with moderate or severe disease. With the exception of people with severe disease in 1998, the prevalence of ICH among people with all severity levels of disease and over all years was under 1% and

relatively stable over the time period. In people with hemophilia B (Figure 11), there was more variability in the prevalence of ICH across severity levels and over time. This is probably a reflection of the smaller number of people with Hemophilia B enrolled in UDC.

In Table 12, nearly one-half of people with severe hemophilia and nearly one-third of people with severe VWD report some restriction of activity. Data in Table 13 demonstrates that the average joint limitation value for people with Type 3 VWD (68.2) falls between the value for people with mild (54.7) and moderate (84.5) hemophilia.

Figures 12 and 13 show natural or acquired immunity to hepatitis A by age and region in people with hemophilia. Overall immunity rates are approximately 60%. Figure 14 shows that among people with VWD, the prevalence of natural or acquired immunity to hepatitis A averages around 40%, with people over 60 having a higher prevalence of immunity.

Immunity to hepatitis B is illustrated in Figures 15, 16 and 17. Immunity to hepatitis B is higher (approximately 80% of people with hemophilia and 70% of people with VWD are immune) than to hepatitis A which is likely due to increased rates of vaccination against hepatitis B.

Prevalence of hepatitis C infection for people with hemophilia and VWD is shown in Figure 18. Higher infection rates in adults reflect exposure to the disease prior to viral inactivation of factor products. Figure 19 shows that immunity to hepatitis A among people with hemophilia who are also infected with hepatitis C varies between 55-75% across regions.



Prevalence of HIV among people with hemophilia and VWD is shown in Figure 20. HIV infection rates are extremely low in all people with VWD; however, approximately one-third of people with hemophilia between the ages of 21 and 60 years are HIV-infected.

Tables 14 and 15 illustrate the number of people with hemophilia who use continuous prophylaxis by age group and severity. Continuous prophylaxis use drops off markedly in people who are  $\geq 21$  years old. Prophylaxis is used most often by people with severe disease regardless of hemophilia type, less so by people with moderate disease, and rarely by people with mild disease. Among people with both moderate and severe disease, continuous prophylaxis use increases through the mid-teens and begins to decrease in the late teens, the decline in use occurring slightly earlier among people with severe type B hemophilia. Continuous prophylaxis use by people with moderate disease increases more slowly than in those with severe disease. One reason for this pattern of use could be that it may take longer for these people to experience enough bleeding episodes to merit the initiation of continuous prophylaxis.

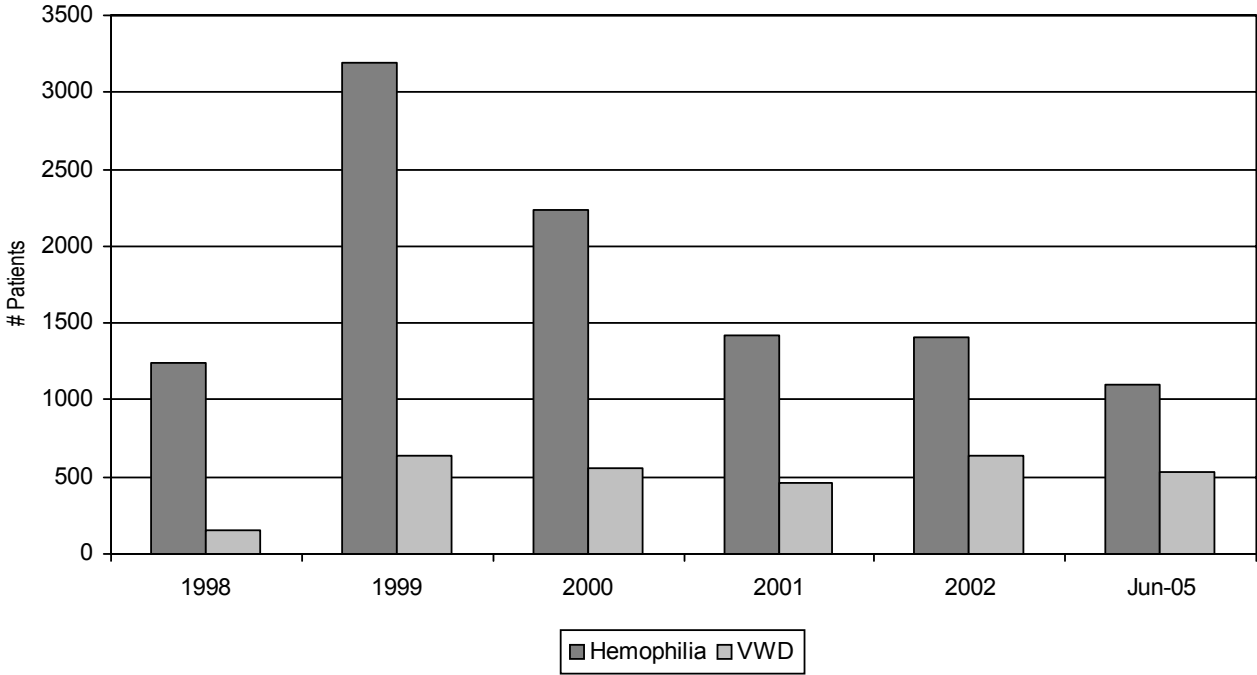
Table 16 shows the prevalence of overweight and obese people enrolled in UDC. People with hemophilia and VWD aged 13 to 19 years are almost twice as likely to be overweight as children of the same age group in the U.S. population. Obesity, which could only be compared for those 20 or older, is at a similar rate as in the U.S. population for people with hemophilia but appears higher for people with VWD than in the general population.

Figure 21 shows no significant difference between people with hemophilia and those with VWD in the proportion who are overweight. However, the proportion of people with VWD who are obese is significantly higher than that among those with hemophilia ( $p \leq 0.05$ ).

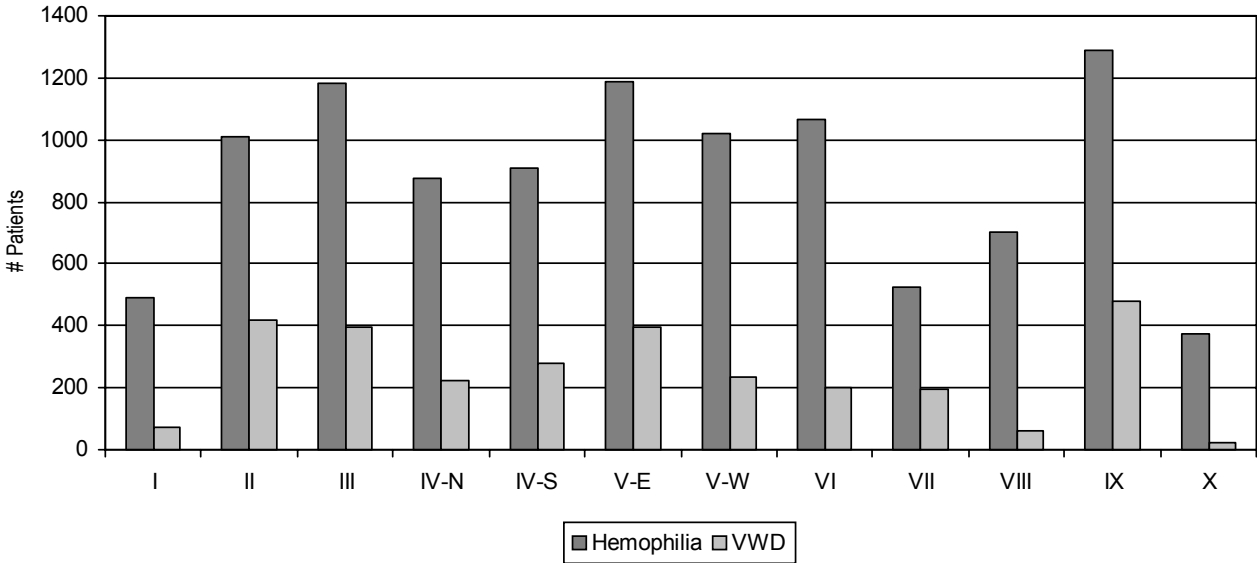
In Table 17, among people with hemophilia, there is an inverse relationship between disease severity and being overweight or obese. Compared to people with hemophilia, there appears to be less correspondence between overweight and obesity prevalence and severity among people with VWD.

Figure 22 shows the regional distribution of overweight or obese persons with hemophilia and VWD. The prevalence of overweight and obesity among people with hemophilia across regions is between 40% and 60%, while the prevalence varies between 40% and 70% among people with VWD.

**Figure 1. New enrollment in UDC, May 1998 –December 2003**

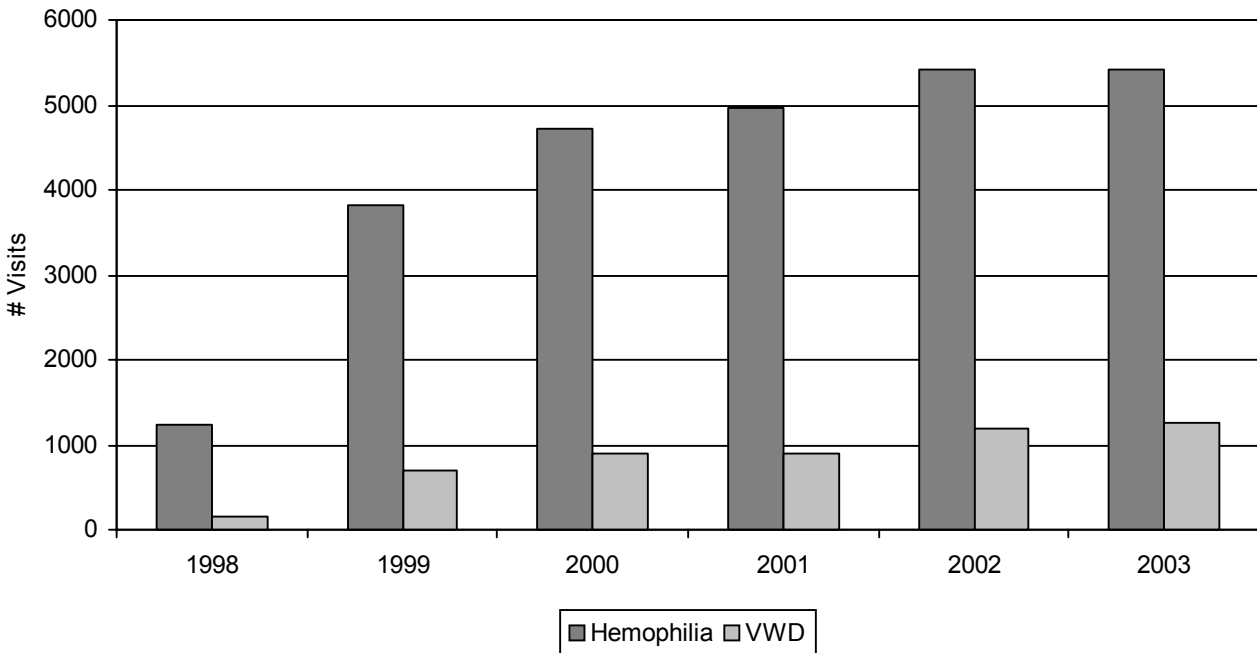


**Figure 2. Total patients enrolled in UDC by region\* through December 2003**

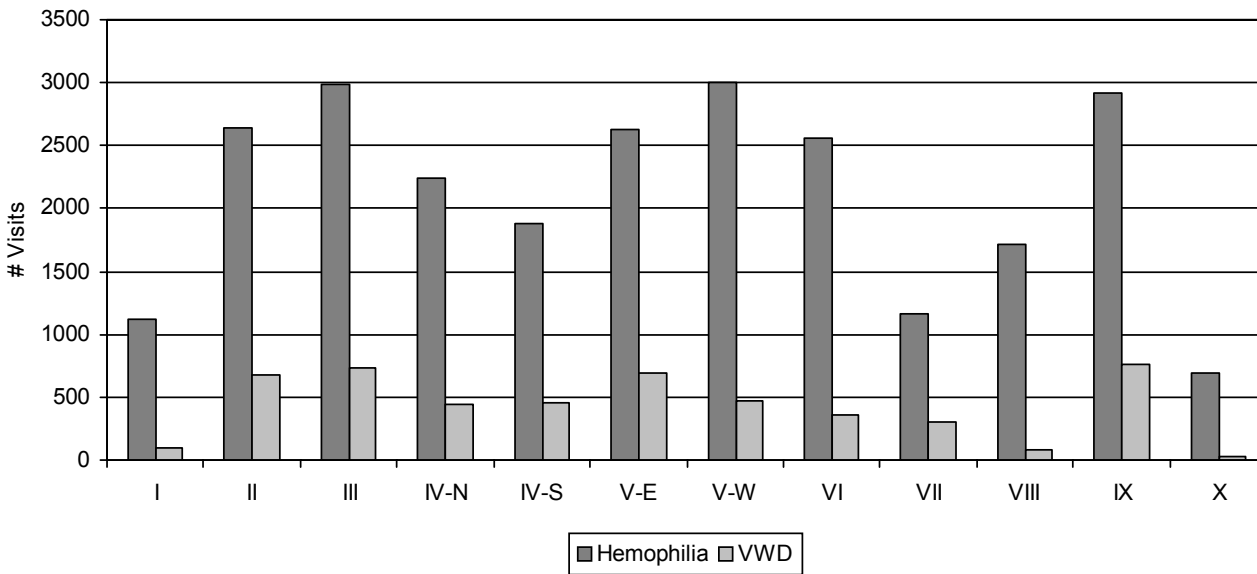


\*See map (page38) for regional designations.

**Figure 3. UDC visits by year, May 1998- December 2003**

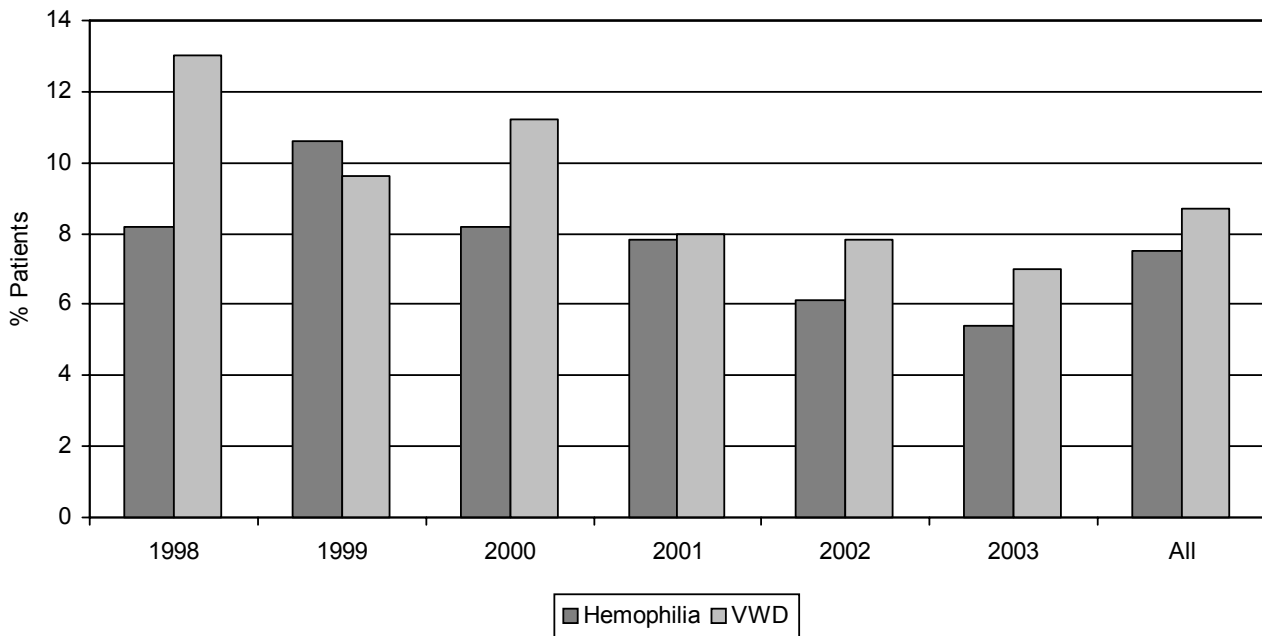


**Figure 4. Total UDC visits by region\* through December 2003**

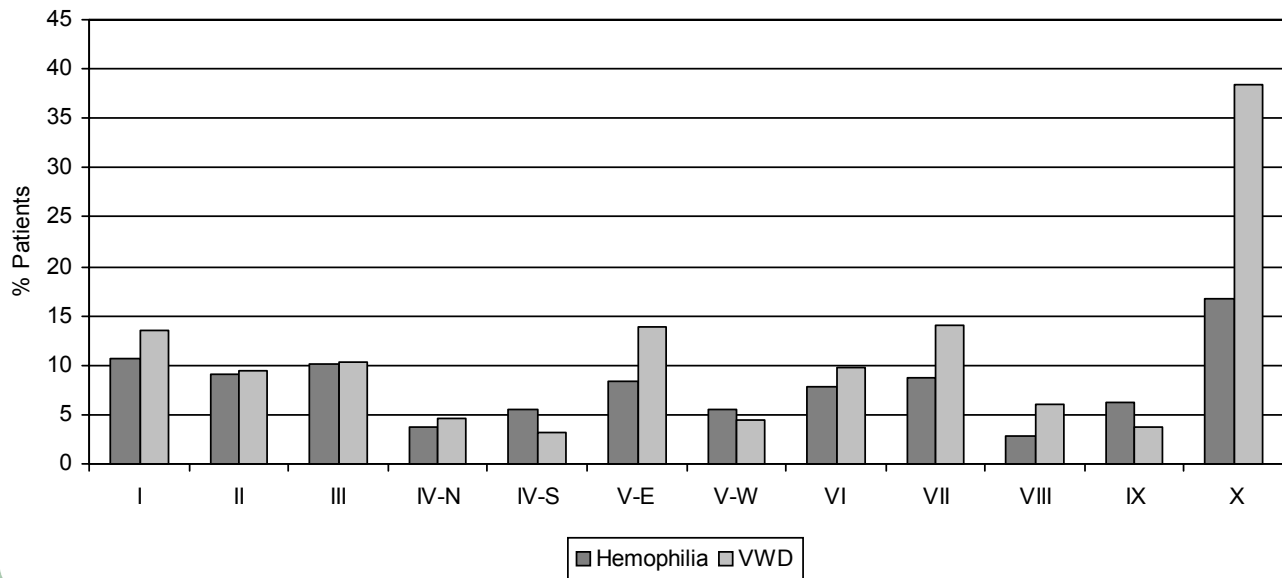


\*See map (page 38) for regional designations.

**Figure 5. Refusal rates in UDC by year, May 1998 – December 2003**

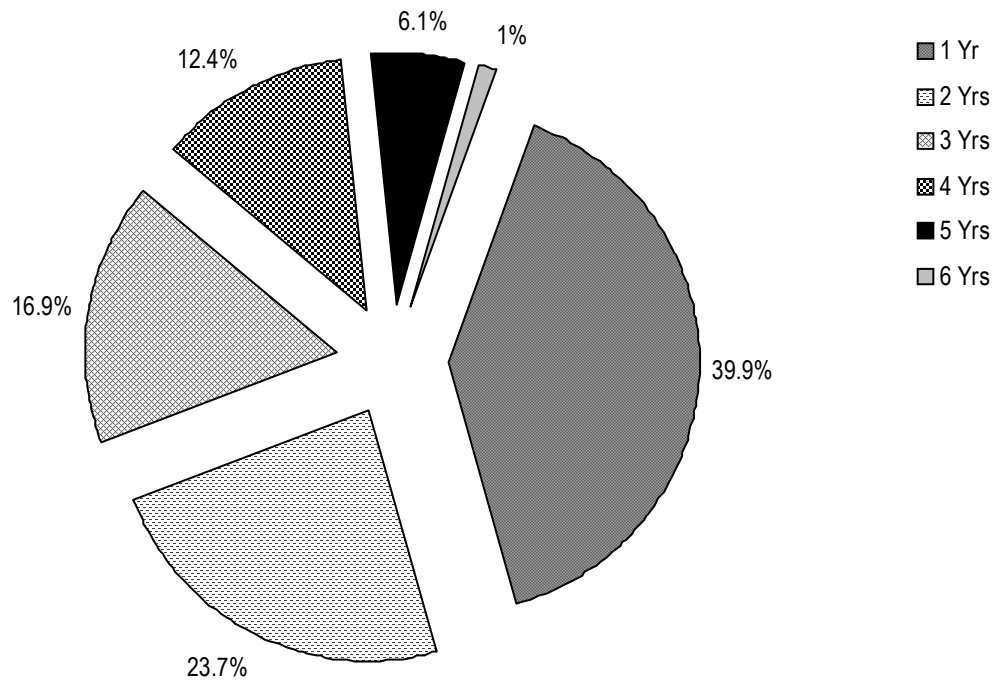


**Figure 6. Refusal rates in UDC by region\*, May 1998 – December 2003**

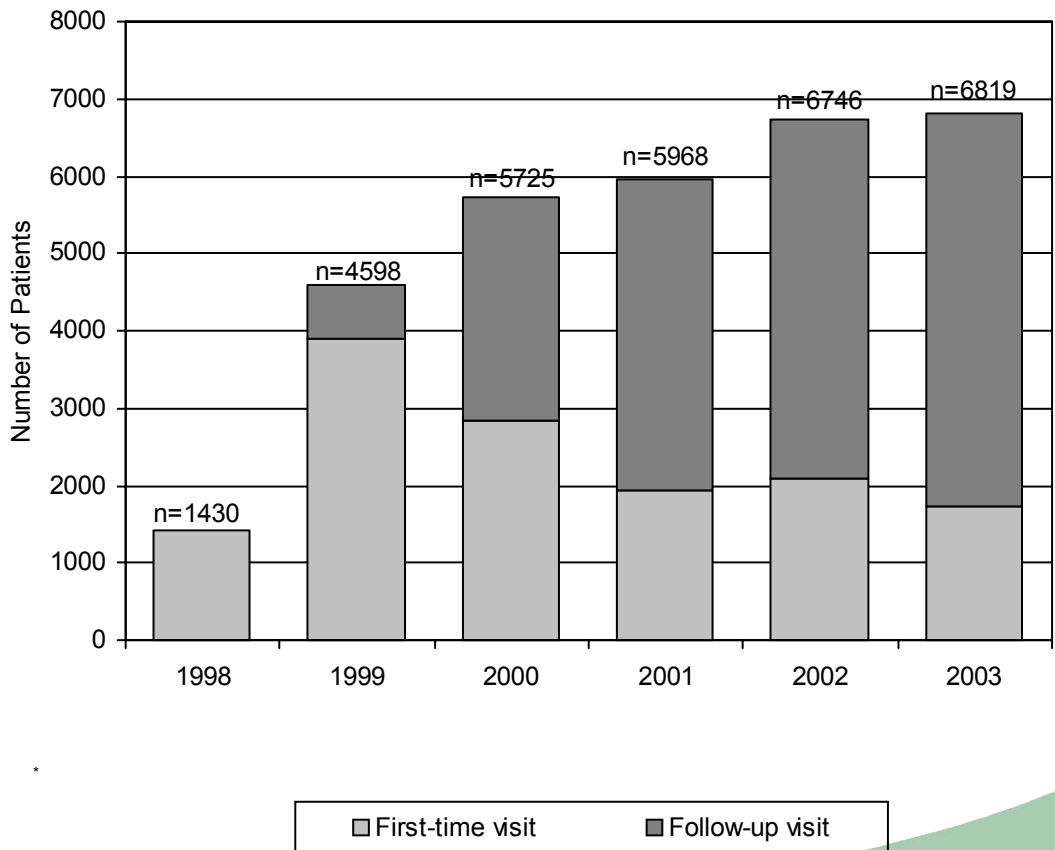


\*See map (page38) for regional designations.

**Figure 7. Number of years of follow-up for people enrolled in UDC**



**Figure 8. Visits by UDC participants through December 2003**



**Table 1. Demographic characteristics of people\* enrolled in UDC**

Characteristic	Hemophilia		VWD			
	A (n =8087)	B (n=2183)	(n = 2441)			
	Number	Percent	Number	Percent	Number	Percent
<b>Age Group (yrs)</b>						
2-10	1824	21.8	471	20.6	565	19.0
11-20	2623	31.4	657	28.8	1153	38.7
21-40	2366	28.5	612	26.8	650	21.8
41-60	1244	14.9	424	18.6	457	15.3
>60	288	3.4	120	5.3	156	5.2
<b>Race/Ethnicity</b>						
White	5718	68.4	1717	75.2	2215	74.3
African American	1044	12.5	248	10.9	173	5.8
Hispanic	1095	13.1	218	9.5	366	12.3
Asian/Pacific Islander	233	2.8	33	1.4	80	2.7
Native American	65	0.8	17	0.7	19	0.6
Other	208	2.5	51	2.2	126	4.2
<b>Sex</b>						
Male	8182	97.8	2205	96.5	1237	41.5
Female	183	2.2	79	3.5	1744	58.5

\*Sixty-five people were reported to have both hemophilia and VWD (these people are included in analyses as hemophilia patients only and not VWD patients). A total of 337 people had a bleeding disorder other than hemophilia or VWD.



**Table 2. Sources\* of health care reimbursement listed by people enrolled in UDC**

Reimbursement source	Hemophilia (n = 10649)		VWD (n = 28981)	
	Number	% of Total	Number	% of Total
Commercial Insurance	1914	18.0	640	21.5
Commercial Insurance HMO	1994	18.7	696	23.4
Commercial Insurance PPO	2200	20.7	661	22.2
Medicare	912	8.6	152	5.1
Medicare HMO	96	0.9	31	1.0
Medicaid	2206	20.7	388	13.0
Medicaid HMO	595	5.6	222	7.5
CHAMPUS	77	0.7	41	1.4
State high risk plan	341	3.2	45	1.5
Other	1421	13.3	396	13.3
Uninsured	426	4.0	91	3.0

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

**Table 3. Disease severity of people enrolled in UDC**

	Number	Percent
<b>Hemophilia</b>	<b>10649</b>	
Mild	2678	25.2
Moderate	2444	23.0
Severe	5527	51.9
<b>VWD</b>	<b>22981</b>	
Type 1	2113	70.9
Type 2	330	11.1
Type 3	217	7.3
Other/Unknown	321	10.8

**Table 4. Bleeding episodes\* among people enrolled in UDC by prophylaxis use and disease severity**

**No Prophylaxis**

Bleeding site	Hemophilia			VWD		
	Mild n=2664	Moderate n=2180	Severe n=3755	Type 1 n=2101	Type 2 n=327	Type 3 n=210
Joint *	0.6 (±2.5)	3.1 (±7.7)	8.7 (±12.4)	0.1 (±1.1)	0.2 (±1.4)	1.8 (±6.7)
Muscle*	0.3 (±1.0)	0.9 (±2.3)	2.1 (±4.8)	0.1 (±1.2)	0.1 (±0.8)	0.4 (±1.3)
Other*	0.9 (±5.2)	1.4 (±6.1)	1.8 (±6.8)	3.5 (±10.5)	3.4 (±11.8)	6.6 (±16.9)
<b>All sites</b>						
Mean (±SD)	1.8 (±6.1)	5.4 (±10.6)	12.6 (±15.9)	3.7 (±10.7)	3.7 (±11.9)	8.8 (±19.7)
Median	0	2	8	0	1	2

**Prophylaxis Used**

Bleeding Site	Hemophilia	
	Moderate n =264	Severe n=1772
Joint *	3.6 (±7.3)	2.9 (±7.3)
Muscle*	1.0 (±2.4)	0.9 (±4.7)
Other*	1.0 (±2.2)	1.1 (±4.3)
<b>All sites</b>		
Mean (±SD)	5.6 (±8.9)	4.9 (±10.3)
Median	3	2

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



**Table 5. Liver disease and intravenous access device infections among people enrolled in UDC**

	Hemophilia (n = 10649)		VWD (n = 2981)	
	Number	% of Total	Number	% of Total
<b>Risk Factors for liver disease</b>				
Past/present hepatitis B virus infection	586	5.5	19	0.6
Past/present hepatitis C virus infection	1309	12.2	65	2.2
History of alcohol abuse	434	4.1	13	0.4
Other	157	1.5	22	0.7
None	8895	83.5	2877	96.9
<b>Signs or symptoms of liver disease (During the last year)</b>				
Jaundice	70	0.7	2	0.1
Ascites	65	0.6	5	0.2
Varices	55	0.5	4	0.1
Other	95	0.9	12	0.4
None	10436	98.0	2962	99.4
<b>Laboratory markers of liver disease</b>				
Chronically elevated ALT/AST levels	1528	14.4	67	2.3
Elevated prothrombin time in the last year	205	1.9	62	2.1
<b>Therapy for chronic viral hepatitis</b>				
Any therapy	709	6.7	33	1.1
Successful therapy	204	28.9*	11	34.4*
<b>Intravenous access devices (IVAD)</b>				
Used an IVAD in the last year	1222	11.5	63	2.1
IVAD infection in the last year	137	11.2**	2	3.2**

\*Proportion of people who received any therapy for chronic viral hepatitis.

\*\*Proportion of people who used an IVAD in the last year.

**Table 6. Treatment type for people with hemophilia enrolled in UDC**

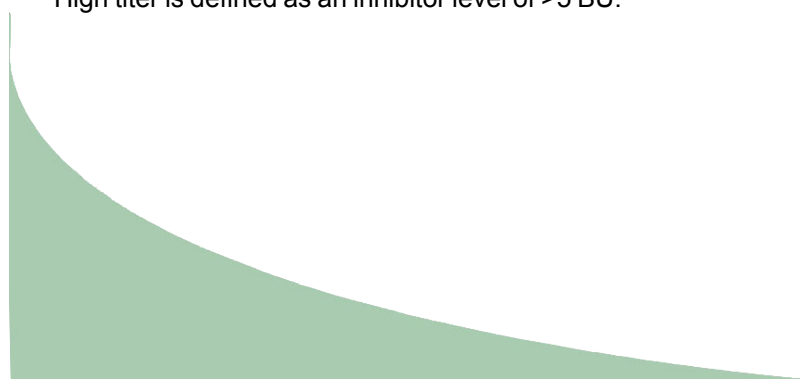
Treatment	Mild		Moderate		Severe	
	Number	Percent	Number	Percent	Number	Percent
Episodic care	2641	98.6	2092	85.6	3239	58.6
Intermittent Prophylaxis	22	0.9	80	3.3	440	8.0
Continuous Prophylaxis	14	0.5	263	10.8	1764	31.9
<b>Total</b>	<b>2678</b>		<b>2444</b>		<b>5527</b>	

\*Prophylaxis is considered continuous when administered on a regular basis and is expected to continue indefinitely.

**Table 7. Prevalence of current inhibitors by titer\* among people with hemophilia enrolled in UDC**

Severity	Number	Hemophilia A		Hemophilia B		
		Low titer	High titer	Number	Low titer	High Titer
Mild	2089	17 (0.8%)	4 (0.2%)	589	0 –	0 –
Moderate	1627	56 (3.4%)	19 (1.2%)	817	1 (0.1%)	3 (0.4%)
Severe	4649	263 (5.7%)	254 (5.5%)	878	20 (2.3%)	25 (2.9%)

Inhibitor titer is determined by the highest reported inhibitor titer for any visit. Low titer is defined as an inhibitor level of 0.5 – 5 Bethesda units (BU). High titer is defined as an inhibitor level of >5 BU.



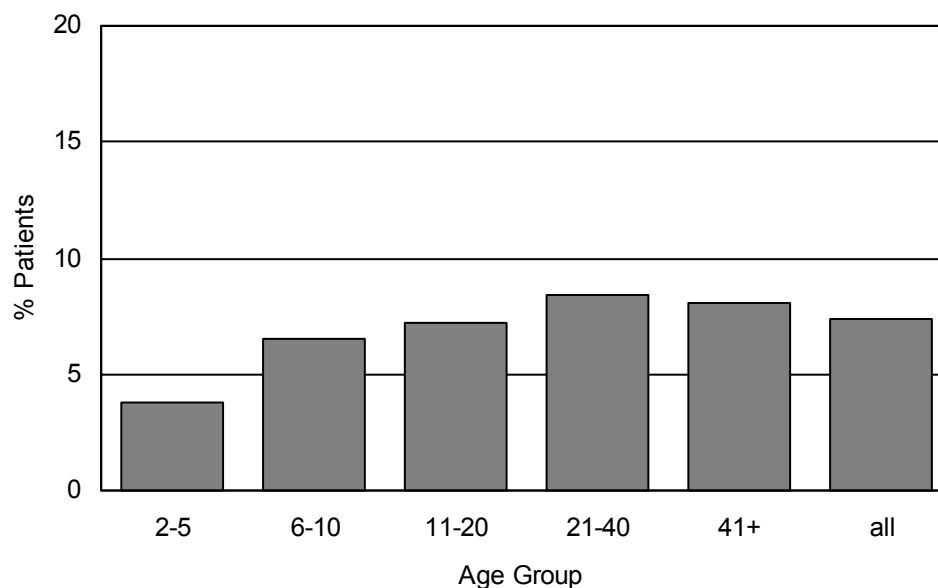
**Table 8. Blood and factor products used\* by people enrolled in UDC**

Treatment product	Hemophilia A n = 8365		Hemophilia B n = 2284		VWD n = 2981	
	Number	Percent	Number	Percent	Number	Percent
Recombinant factor	5243	62.7	1281	56.1	13	0.4
Monoclonal factor VIII	1426	17.1	3	0.1	4	0.1
Other human factor VIII	182	2.2	2	0.1	581	19.5
Porcine factor VIII	10	0.1	0	--	0	--
Purified factor IX	6	0.1	464	20.3	0	--
Prothrombin complex	32	0.4	26	1.1	0	--
Activated prothrombin complex	290	3.5	22	1.0	0	--
Cryoprecipitate of FFP	50	0.6	6	0.3	38	1.3
Desompressin	680	8.1	9	0.4	1250	41.9
None used	973	11.6	520	22.8	1136	38.1

\*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.

**Figure 9. Prevalence of multiple treatment product use among people with hemophilia in UDC who use treatment products by age**



**Table 9. Prevalence of multiple factor product use among people with hemophilia by treatment type**

Treatment	Total using any product	Number using Multiple Products (%)
Episodic Care	7835	624 (8.0)
Intermittent Prophylaxis	537	43 (8.0)
Continuous Prophylaxis	2036	84 (4.1)

\*Total number of people using any product is not equal to total number of people with hemophilia because people on immune tolerance are not included in this table.

**Table 10. Prevalence of multiple factor product use among people with hemophilia by disease severity**

Severity	Total using any product	Number using Multiple Products (%)
Mild	2616	275 (10.5)
Moderate	2406	127 (5.3)
Severe	5480	372 (6.8)
ALL	10502	774 (7.4)



**Table 11. Prevalence of multiple factor product use among people with hemophilia by current inhibitor titer**

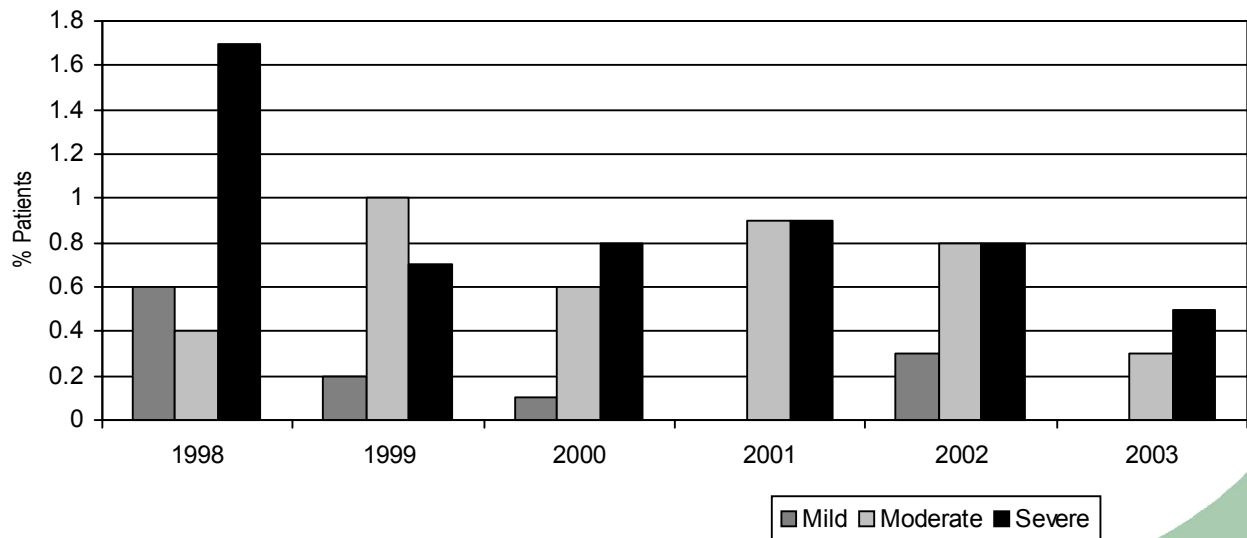
Hemophilia A	Total using any product	Number on Multiple Products (%)
Negative	5420	318 (6.1)
Low Titer	334	44 (13.2)
High Titer	274	90 (32.9)
Missing	2397	236 (9.9)

Hemophilia B	Total using any product	Number on Multiple Products (%)
Negative	1349	38 (2.8)
Low Titer	19	1 (5.3)
High Titer	27	121 (44.4)
Missing	862	35 (4.1)

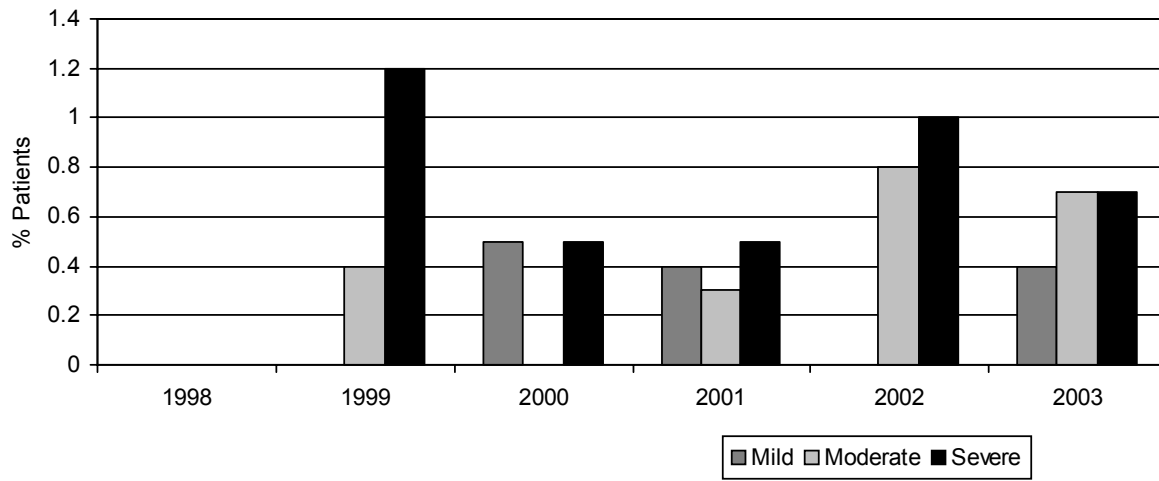
\* Inhibitor titer is determined by the highest reported inhibitor titer for any visit. Low titer is defined as an inhibitor level of 0.5 – 5 Bethesda units (BU). High titer is defined as an inhibitor level of >5 BU.

**Figure 10. Prevalence of intra-cranial hemorrhage\* in people with hemophilia A by severity, May 1998-December 2003**



\*Occurrence since last annual visit

**Figure 11. Prevalence of intra-cranial hemorrhage in people with hemophilia B by severity, May 1998 - December 2003**



\*Occurrence since last annual visit

**Table 12. Joint complications among people enrolled in UDC**

	Hemophilia			VWD		
	Mild n (%)	Moderate n (%)	Severe n (%)	Type 1 n (%)	Type 2 n (%)	Type 3 n (%)
Target joint *	158 (5.9)	506 (20.7)	1920 (34.7)	35 (1.7)	5 (1.5)	4 (15.7)
Invasive procedure	81 (3.0)	82 (3.4)	498 (9.0)	28 (1.3)	2 (0.6)	15 (6.9)
Joint infection	18 (0.7)	7 (0.3)	73 (1.3)	21 (1.0)	2 (0.6)	2 (0.9)
Used cane	342 (12.8)	536 (21.9)	1644 (29.7)	117 (5.5)	17 (5.2)	42 (19.4)
Used wheelchair	64 (2.4)	126 (5.2)	558 (10.1)	35 (1.7)	9 (2.7)	13 (6.0)
Any activity restriction	437 (16.3)	686 (28.1)	2289 (41.4)	180 (8.5)	32 (9.7)	60 (27.7)

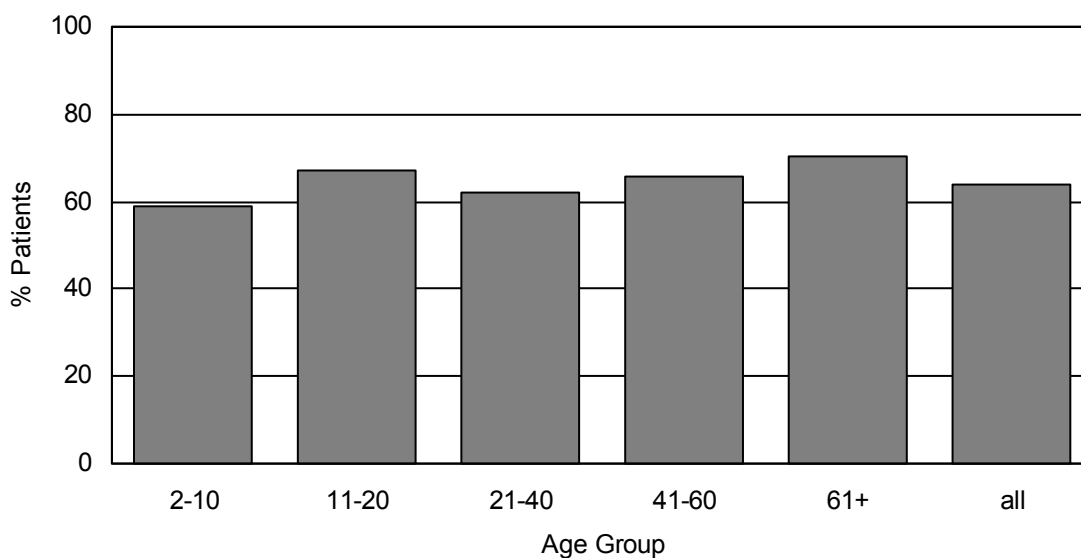
\*Please see Technical Notes (page 32) for the definition of a target joint

**Table 13. Joint limitations among people enrolled in UDC**

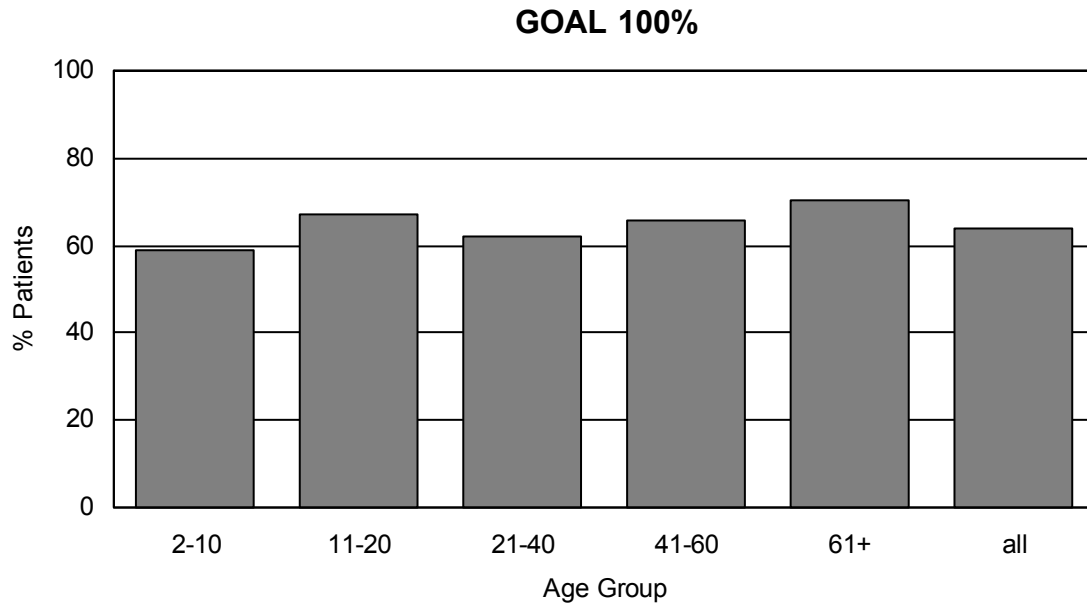
	Hemophilia			VWD		
	Mild	Moderate	Severe	Type 1	Type 2	Type 3
Number of patients	2428	2204	4741	1942	304	192
Mean indicator* value	54.7	84.5	148.0	20.2	27.9	68.2
Standard deviation	107.0	151.1	211.7	86.5	80.6	111.7

\*Indicator is the total number of degrees of range of motion less than normal for five joints. The joint motions measured and normal values used (in parentheses) are: hip extension (30); hip flexion (120); knee flexion (135); knee extension (0); shoulder flexion (180); elbow flexion (150); elbow extension (0); elbow pronation and supination (80); ankle dorsiflexion (20); ankle plantar flexion (50). Any hyperextension of the knee or elbow is included in the calculation. In UDC, limitations in knee and elbow extension are recorded as negative numbers. Patients with missing measures for any of the joints are excluded from the analyses. As an example, patients with mild hemophilia have on average 55.6 degrees less than normal range of motion across ten joints. Because the sum of all of the normal measures is 1,690 degrees, this represents an overall 3.3% loss in range of motion.

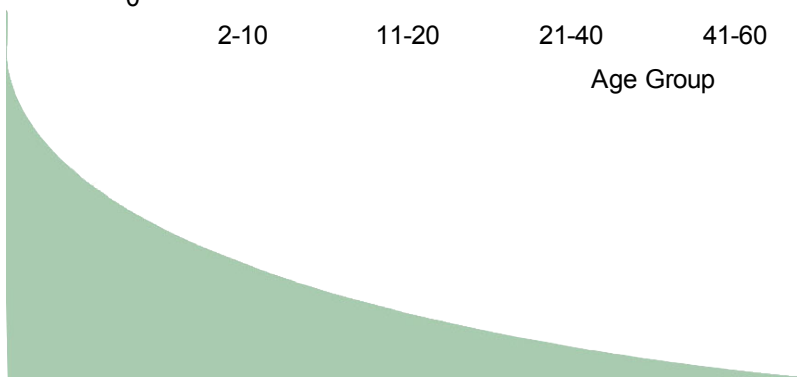
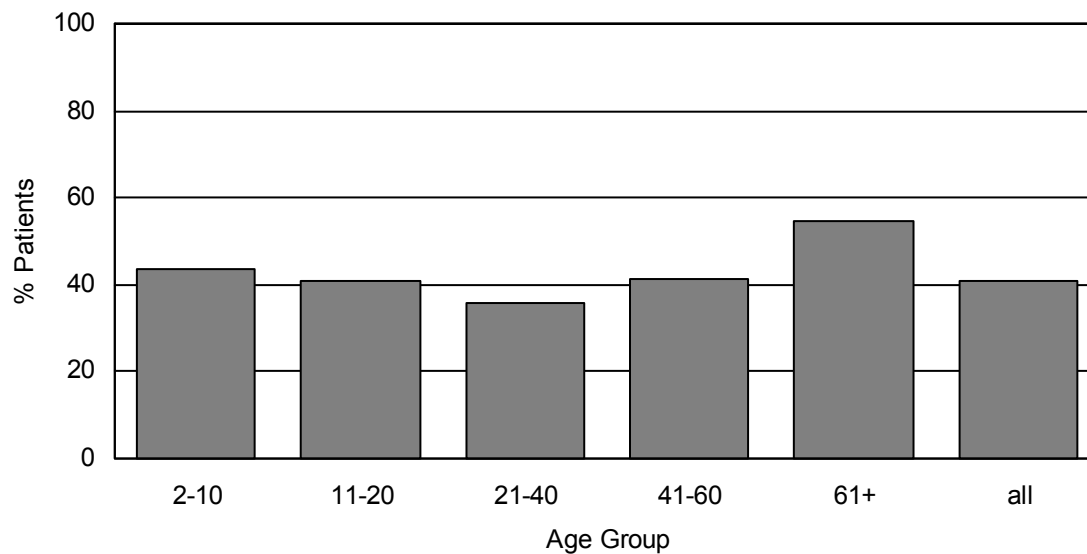
**Figure 12. Prevalence of natural or acquired immunity to hepatitis A virus among people with hemophilia enrolled in UDC**



**Figure 13. Regional distribution of natural or acquired immunity to hepatitis A virus among people with hemophilia enrolled in UDC**

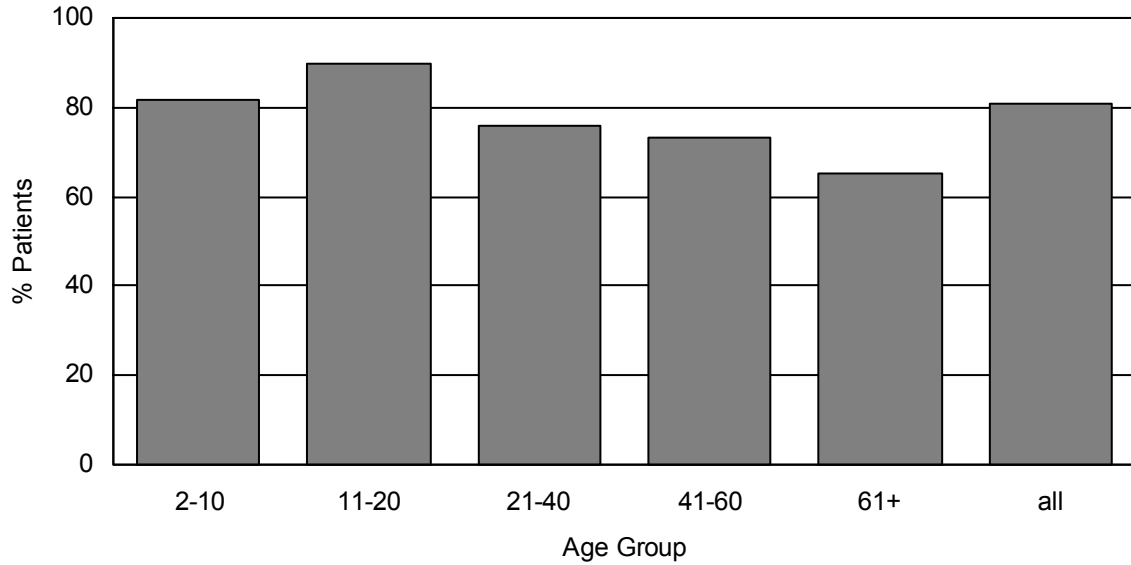


**Figure 14. Prevalence of natural or acquired immunity to hepatitis A virus among people with VWD enrolled in UDC**

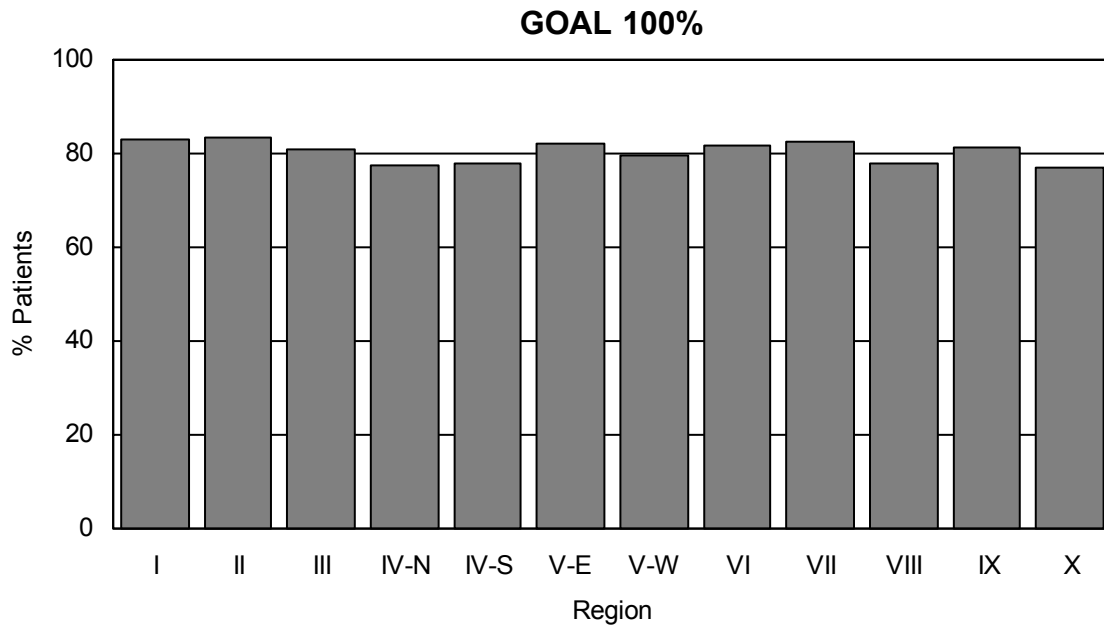




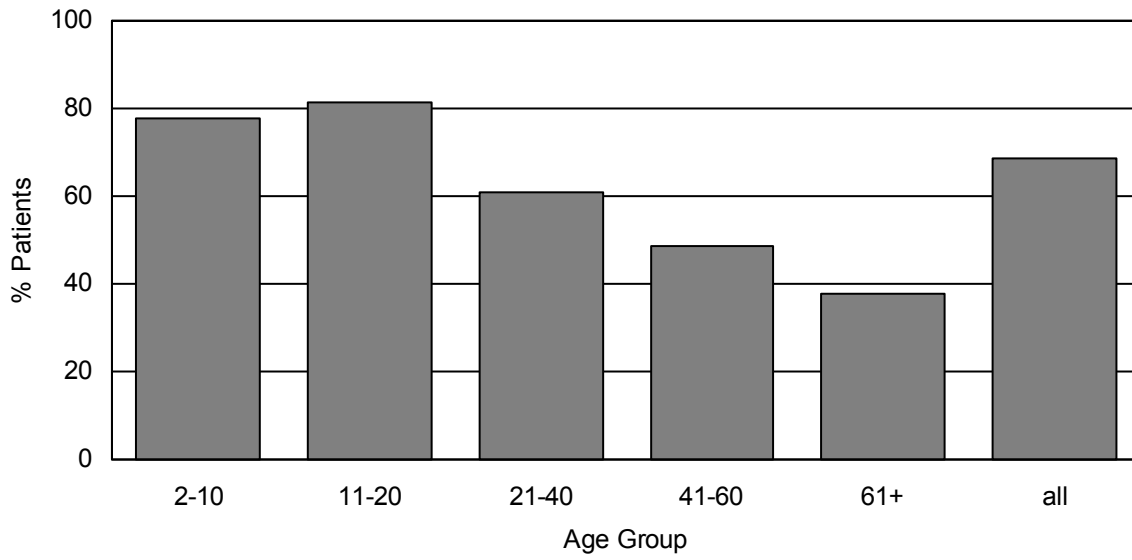
**Figure 15. Prevalence of natural or acquired immunity to hepatitis B virus among people with hemophilia enrolled in UDC**



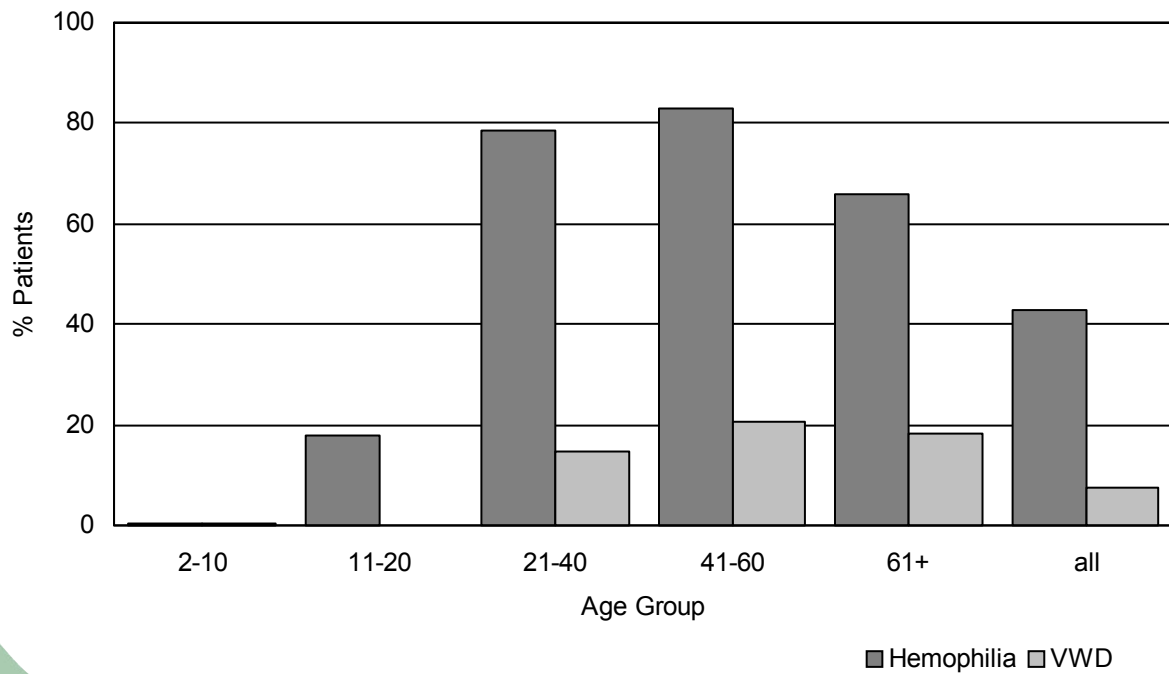
**Figure 16. Regional distribution of natural or acquired immunity to hepatitis B virus among people with hemophilia enrolled in UDC**



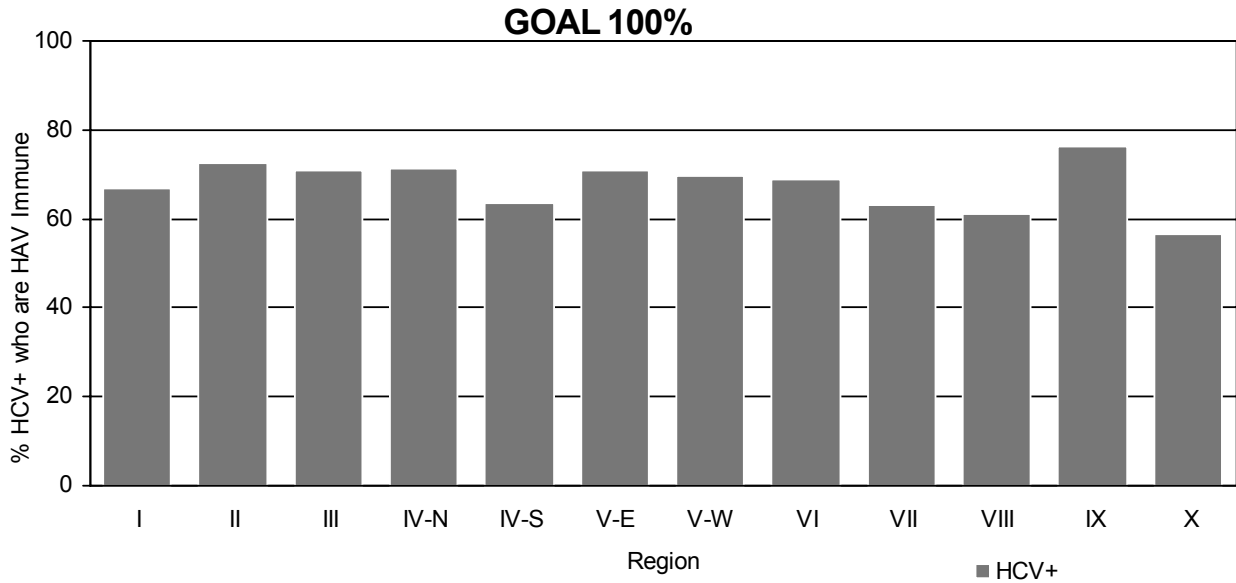
**Figure 17. Prevalence of natural or acquired immunity to hepatitis B virus among people with VWD enrolled in UDC.**



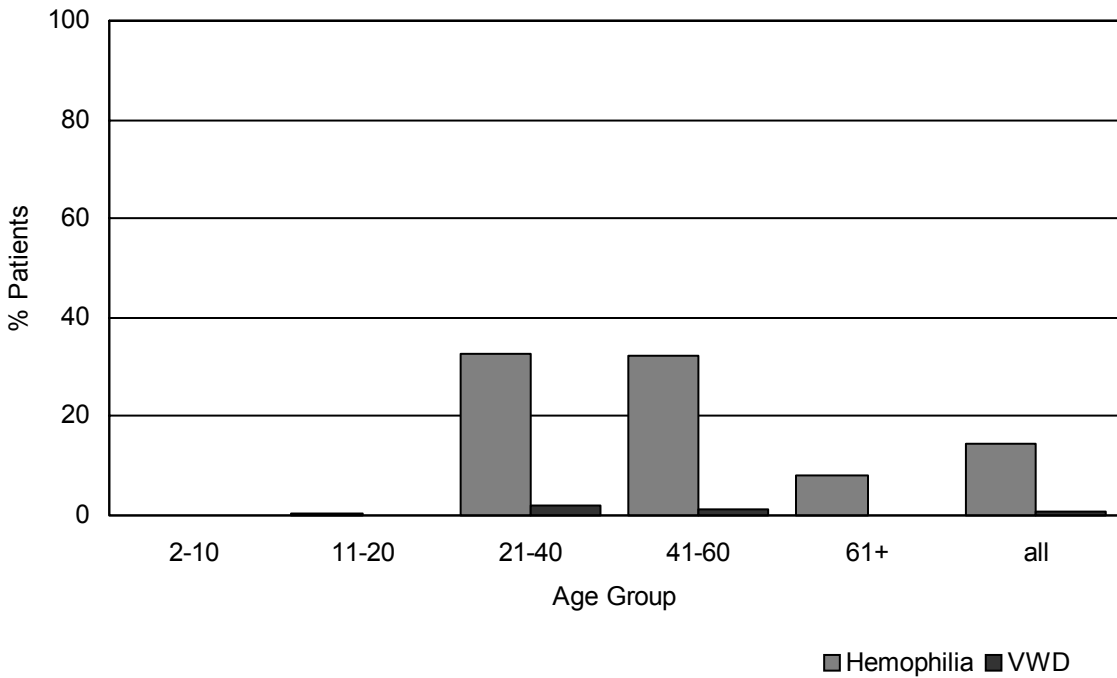
**Figure 18. Prevalence of hepatitis C virus infection among people with bleeding disorders enrolled in UDC**



**Figure 19. Prevalence of natural or acquired immunity to hepatitis A among people with hemophilia and infected with hepatitis C enrolled in UDC**



**Figure 20. Prevalence of human immunodeficiency virus infection among people with bleeding disorders enrolled in UDC**



**Table 14 Hemophilia A: Number of people on continuous prophylaxis**

Age Group (years)	Level of Severity					
	Mild		Moderate		Severe	
	Total	N (%)	Total	N (%)	Total	N (%)
2-5	85	1 (1.2)	100	11 (11.0)	395	196 (49.6)
6-10	282	4 (1.4)	269	53 (19.7)	693	410 (59.2)
11-15	313	2 (1.0)	285	74 (26.0)	794	445 (56.1)
16-20	302	2 (0.7)	255	46 (18.0)	674	256 (38.0)
21-25	188	0 (0.0)	142	8 (5.6)	550	109 (19.8)
31-30	116	0 (0.0)	71	2 (2.8)	290	24 (8.3)
31+	750	1 (0.1)	467	22 (4.7)	1172	89 (7.6)

**Table 15. Hemophilia B: Number of people on continuous prophylaxis**

Age Group (years)	Level of Severity					
	Mild		Moderate		Severe	
	Total	N (%)	Total	N (%)	Total	N (%)
2-5	24	0 (0.0)	57	3 (5.3)	65	30 (46.2)
6-10	70	1 (1.4)	116	11 (9.5)	139	67 (48.2)
11-15	86	1 (1.2)	138	19 (13.8)	122	52 (42.6)
16-20	79	0 (0.0)	112	6 (5.4)	120	35 (29.2)
21-25	43	0 (0.0)	66	3 (4.6)	78	9 (11.5)
31-30	26	0 (0.0)	51	3 (5.9)	62	6 (9.7)
31+	249	2 (0.8)	251	2 (0.8)	281	25 (8.9)

**Table 16. Prevalence of overweight and obese persons in UDC and the US population****Overweight**

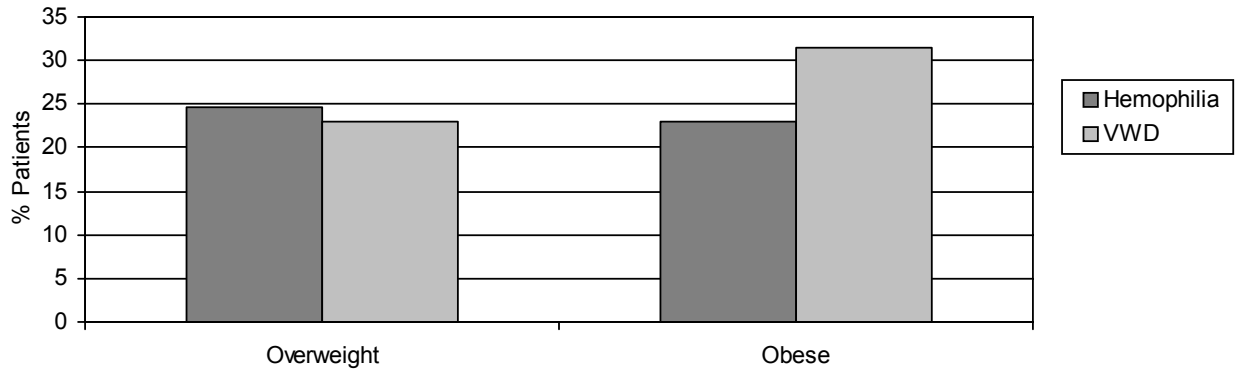
Age Group	Hemophilia	VWD	US Population*
2-12	16.4%	16.6%	13.7%
13-19	18.2%	17.5%	11.5%
20+	32.4%	30.2%	32.6%

**Obese**

Age Group	Hemophilia	VWD	US Population*
20+	23.0%	31.4%	22.3%

\*Based on data from the third National Health and Nutrition Examination Survey

**Figure 21. Prevalence of overweight and obesity\* among people in UDC**



\*Proportion of people who are obese with VWD is significantly higher than the proportion of people with hemophilia who are obese ( $p \geq 0.05$ ).

**Table 17. Prevalence of overweight and obesity among UDC participants by hemophilia severity and VWD type**

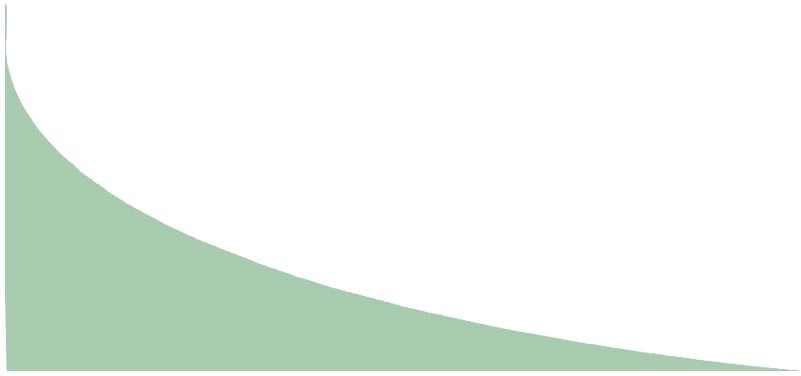
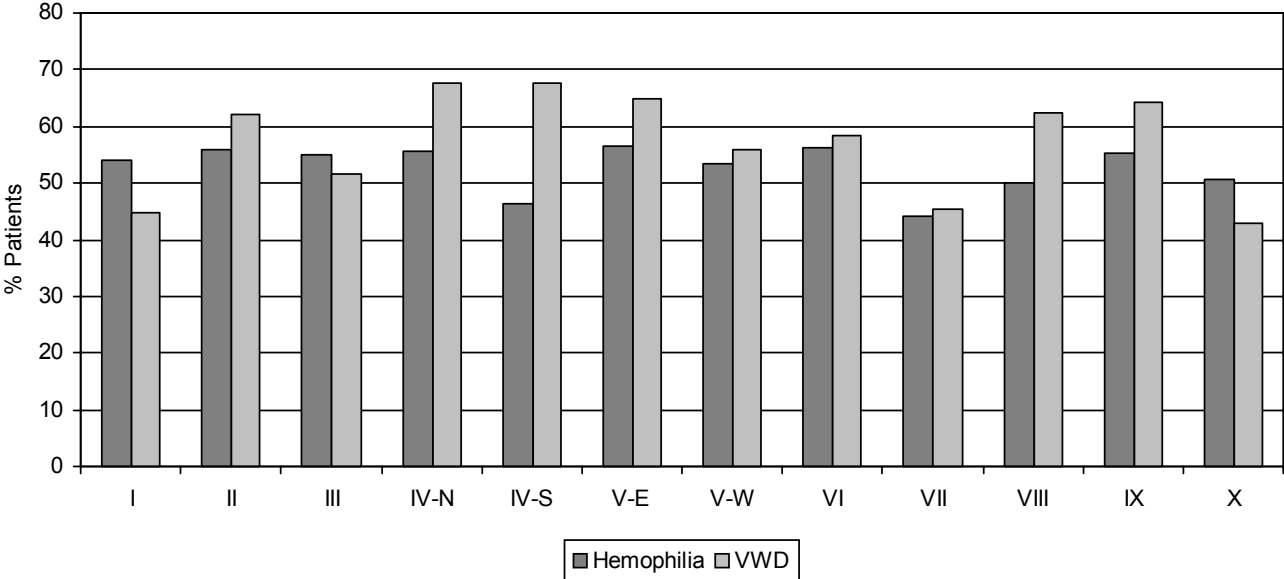
***Hemophilia***

Severity	Overweight (all ages)	Obese (age 20+)
Mild	26.4%	28.8%
Moderate	25.5%	24.8%
Severe	23.5%	18.9%

***VWD***

Type	Overweight (all ages)	Obese (age 20+)
Type 1	22.5%	32.5%
Type 2	23.5%	27.3%
Type 3	26.8%	32.7%
Other/Unknown	22.8%	29.1%

**Figure 22. Prevalence of overweight and obesity among people in UDC (age  $\geq 20$ ) by region**



# Technical Notes

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## 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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Scarborough, ME  
Dartmouth-Hitchcock Hemophilia Center  
Lebanon, NH  
Rhode Island Hospital  
Providence, RI  
Vermont Regional Hemophilia Center  
Burlington, VT  
UCONN Hemophilia Treatment Center  
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Syracuse, NY  
SUNY Upstate Medical University-Pediatric  
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The Regional Comprehensive Hemophilia & von  
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UHS Blood Disorder Center  
Johnson City, NY  
Long Island Jewish Medical Center  
New Hyde Park, NY  
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Charlottesville, VA  
Virginia Commonwealth University  
Richmond, VA  
Children's Hospital of the King's Daughters  
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Cardeza Foundation Hemophilia Center  
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Christiana Care Health Services  
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Hemophilia Center of Central Pennsylvania  
Hershey, PA  
Lehigh Valley Hospital  
Allentown, PA  
Hemophilia Center of Western Pennsylvania  
Pittsburgh, PA  
West Virginia University Medical Center  
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Charleston Area Medical Center  
Charleston, WV  
Johns Hopkins University Medical Center  
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Richland Memorial  
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Birmingham, AL  
Miami Comprehensive Hemophilia Center - Adult  
Miami, FL  
Children's Rehabilitation Services  
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Children's Rehabilitation Services  
Birmingham, AL  
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MeritCare Hospital DBA Roger Maris Cancer Center  
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Gundersen Clinic  
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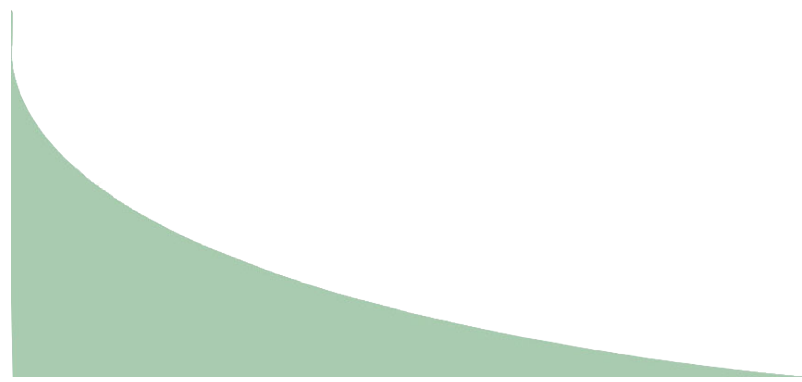
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Sacramento, CA  
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San Francisco, CA  
Orthopedic Hospital of Los Angeles  
Los Angeles, CA  
Children's Hospital, San Diego  
San Diego, CA  
Children's Hospital of Orange County  
Orange, CA  
Children's Hospital Oakland  
Oakland, CA  
City of Hope National Medical Center  
Duarte, CA  
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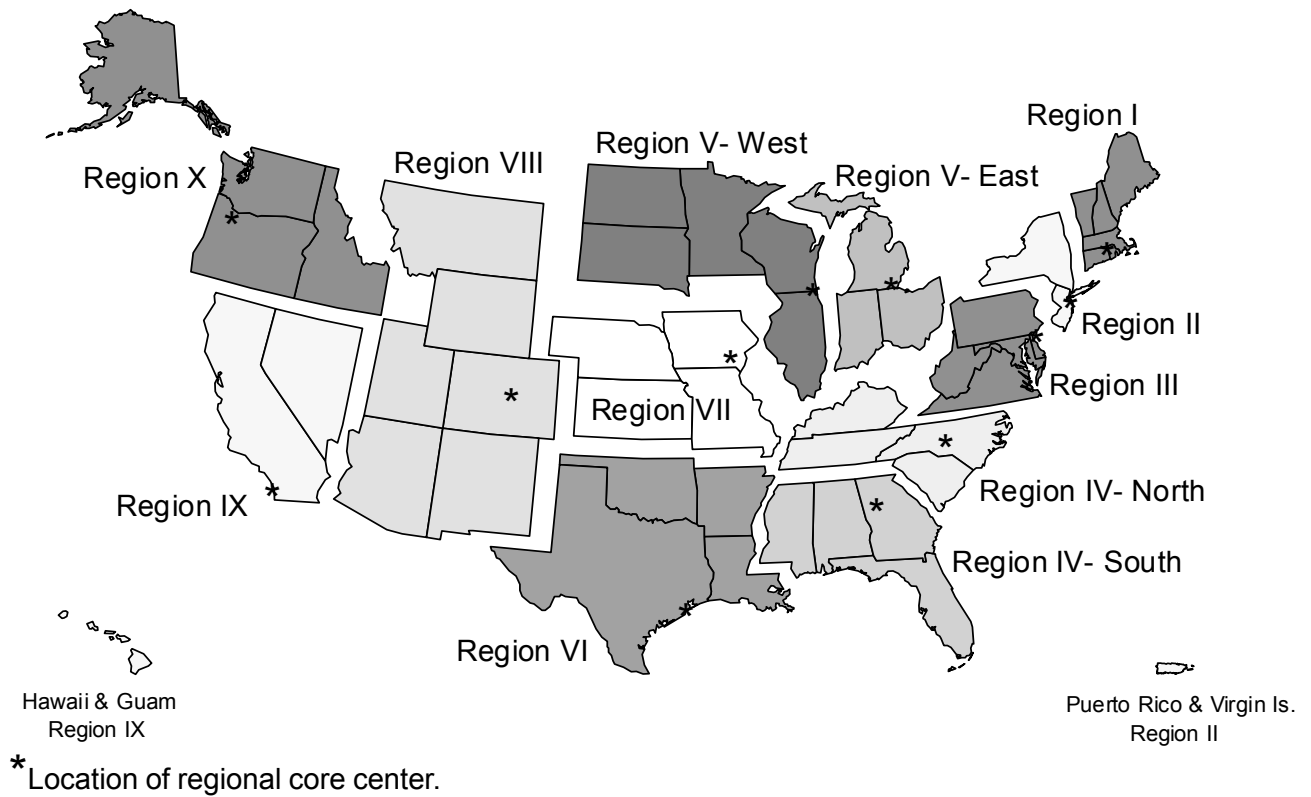
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# Hemophilia Treatment Center Regions



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