Report on the Universal Data Collection Program

Includes data collected from May 1998 through December 2004
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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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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 140 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.

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 2004. For the first time we have included data on children under 2 years of age enrolled in the UDC. Tables and figures that include only people 2 years of age or older are noted.

Since May, 1998, 15,682 people with bleeding disorders have been enrolled, and there have been 38,385 UDC visits. The overall national refusal rate is 7.6 %.

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. The number of UDC visits held per year appears to have plateaued in 2002 and have remained constant through the end of 2004.

Figures 5 and 6 show the refusal rates in UDC from May 1998 through December 2004 by year and region. Refusal rates have generally declined over time but appear to have increased slightly among people with hemophilia and VWD in 2004. The overall refusal rate is 7.3% for people with hemophilia and 8.6% for people with VWD. Refusal rates through December 2004 in regions I through IX remained below 15%, with a low of 3.6% in Region IV-N among people with hemophilia to a high of 14.3% among people with VWD in Region V-E.
Refusal rates in Region X are unusually high due to low numbers of people enrolled in UDC.

Figure 7 shows the follow-up time for people enrolled in UDC. Nearly two-thirds of people enrolled in UDC have had more than one annual visit.

Figure 8 shows the number of people with a UDC visit in each year through December 2004 according to visit type. The number of people with a first time UDC visit has gone down as a proportion of total visits while 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. A little over 50% of people with hemophilia are ≤ 20 years of age and nearly all are males as expected. Over 60% of people with VWD are ≤ 20 years old and patients are more evenly divided among men and women. In both groups, persons under 2 years of age comprise less than 1% of the population. The population distribution by race and ethnicity is similar to that of the general population. With regard to healthcare reimbursement, about 60% of participants have some form of commercial insurance, about 30-35% have government sponsored coverage, and the remainder have other types of insurance. Only about 3-4% of patients are uninsured.

As shown in Table 3, one quarter of people in UDC with hemophilia have mild disease, 23.0% have moderate disease, and 51.5% have severe disease. 71.8% of people in UDC with VWD are classified as having Type 1, 10.6% as having Type 2, 6.8% 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. 271 (31.3%) of the 873 people with hemophilia receiving any therapy for viral hepatitis had successful treatment of the disease. 1293 (11.0%) people with hemophilia had an intravenous access device (IVAD) in the year previous to their most recent visit. Of these, 147 (11.4%) 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 7.9% 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 with hemophilia use recombinant products. Twelve percent of patients with hemophilia A, 24% of those with hemophilia B and 40% of patients with VWD used no product during the year prior to their UDC visit.

The prevalence of multiple product use (Figure 9 and Tables 9-11) has increased when compared to previous UDC reports. In order to more accurately reflect multiple product use, the method used to calculate these data has changed. People who use no products have been excluded from the denominator, and multiple product use is now defined as using more than one product regardless of product type (e.g. a person using Bioclate and Helixate is denoted as using multiple products even though both products are Factor VIII recombinant products).

In Figure 9, multiple factor product use in people with hemophilia using any product is between approximately 20% and 30% for all age groups except those aged 6-10, where multiple product use is now 31.6%. Overall multiple product use is 24.1%. For those under age 2 and from 2-5 years, multiple product use is similar.

Table 9 shows multiple product use is similar, between 22-25%, among people with hemophilia for all treatment types.

People with mild hemophilia have a slightly increased use of multiple factor products (29.3%) than people with moderate (23.9%) or severe (22.4%) disease. The overall prevalence of multiple factor product use among those using at least one factor product is 24.1% (Table 10).

Table 11 shows that among people with Hemophilia A and B, those with a high titer inhibitor are much more likely to use multiple factor products (43.0% and 35.5% 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 (70.5) falls between the value for people with mild (55.1) and moderate (87.1) hemophilia.

Figure 12 shows the prevalence of natural or acquired immunity to hepatitis A by age group and year in people with hemophilia. In every year, the prevalence is higher in the group 21 years of age and older. This figure also
suggests that the immunity levels are decreasing over time.

Figure 13 shows the prevalence of natural or acquired immunity to hepatitis A by region in people with hemophilia. Overall immunity rates are approximately 60% but the rates vary from about 50% in Region VII to nearly 70% in Region IX.

Figure 14 shows the prevalence of natural or acquired immunity to hepatitis A by age group and year among people with VWD. The prevalence of immunity appears to be increasing among those under 21 and decreasing among those ages 21 and older.

Figure 15 shows the prevalence of natural or acquired immunity to hepatitis B by age group and year in people with hemophilia. The prevalence appears to be decreasing in both age groups over time despite the availability and widespread usage of hepatitis B vaccine in childhood.

Figure 16 shows the prevalence of natural or acquired immunity to hepatitis B by region in people with hemophilia. Overall immunity rates are approximately 80% and vary remarkably little between regions.

Figure 17 shows the prevalence of natural or acquired immunity to hepatitis B among people with VWD by age and time. Compared to people with hemophilia, the rates are lower in both age groups but the difference is more pronounced in the older age group. People with VWD are more likely than hemophilia patients to receive blood products that are not virally inactivated such as fresh frozen plasma. Therefore, hepatitis B vaccination may be especially important for this population.

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 ≥21 years old. Interestingly, those less than 2 years of age with severe disease are twice as likely to be on continuous prophylaxis as those with mild or moderate disease in their age category. Furthermore, those with severe disease in this age group, have a similar or higher prevalence of continuous prophylaxis when compared with those in older age groups (or all ages in the case of hemophilia B) with moderate and mild disease. 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 obesity among 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=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 of a 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 just over 70% among people with VWD.
Figure 1. New enrollment in UDC, May 1998 – December 2004

Figure 2. Total patients enrolled in UDC by region* through December 2004

*See map (page 39) for regional designations.
Figure 3. UDC visits by year, May 1998-December 2004

Figure 4. Total UDC visits by region* through December 2004

*See map (page 39) for regional designations.
Figure 5. Refusal rates in UDC by year, May 1998 – December 2004

Figure 6. Refusal rates in UDC by region*, May 1998 – December 2004

*See map (page39) for regional designations.
Figure 7. Number of years of follow-up for people enrolled in UDC

- 1 Yr: 0.6%
- 2 Yrs: 4.1%
- 3 Yrs: 11.6%
- 4 Yrs: 15.8%
- 5 Yrs: 37.9%
- 6 Yrs: 21.8%
- 7 Yrs: 11.6%

Figure 8. Visits by UDC participants through December 2004

- First-time visit
- Follow-up visit

Number of Patients

<table>
<thead>
<tr>
<th>Year</th>
<th>First-time Visit</th>
<th>Follow-up Visit</th>
</tr>
</thead>
<tbody>
<tr>
<td>1998</td>
<td>1425</td>
<td></td>
</tr>
<tr>
<td>1999</td>
<td>4579</td>
<td></td>
</tr>
<tr>
<td>2000</td>
<td>5720</td>
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<td>2001</td>
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<td>2002</td>
<td>6743</td>
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<td>2003</td>
<td>7054</td>
<td></td>
</tr>
<tr>
<td>2004</td>
<td>6872</td>
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</tr>
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Table 1. Demographic characteristics of people* enrolled in UDC

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Hemophilia A (n = 9264)</th>
<th>Hemophilia B (n = 2526)</th>
<th>VWD (n = 3484)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age Group (yrs)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;2</td>
<td>52 (0.6%)</td>
<td>19 (0.8%)</td>
<td>2 (0.1%)</td>
</tr>
<tr>
<td>2-10</td>
<td>2344 (25.3%)</td>
<td>594 (23.5%)</td>
<td>891 (25.6%)</td>
</tr>
<tr>
<td>11-20</td>
<td>2900 (31.3%)</td>
<td>725 (28.7%)</td>
<td>1289 (36.4%)</td>
</tr>
<tr>
<td>21-40</td>
<td>2408 (26.0%)</td>
<td>635 (25.1%)</td>
<td>687 (19.7%)</td>
</tr>
<tr>
<td>41-60</td>
<td>1284 (13.8%)</td>
<td>431 (17.1%)</td>
<td>479 (13.8%)</td>
</tr>
<tr>
<td>&gt;60</td>
<td>276 (3.0%)</td>
<td>122 (4.8%)</td>
<td>156 (4.5%)</td>
</tr>
<tr>
<td><strong>Race/Ethnicity</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>6281 (67.8%)</td>
<td>1891 (74.9%)</td>
<td>2599 (74.6%)</td>
</tr>
<tr>
<td>African American</td>
<td>1139 (12.3%)</td>
<td>274 (10.8%)</td>
<td>208 (6.0%)</td>
</tr>
<tr>
<td>Hispanic</td>
<td>1244 (13.4%)</td>
<td>245 (9.7%)</td>
<td>419 (12.0%)</td>
</tr>
<tr>
<td>Asian/Pacific Islander</td>
<td>266 (2.9%)</td>
<td>37 (1.5%)</td>
<td>94 (2.7%)</td>
</tr>
<tr>
<td>Native American</td>
<td>87 (0.9%)</td>
<td>20 (0.8%)</td>
<td>19 (0.5%)</td>
</tr>
<tr>
<td>Other</td>
<td>247 (2.7%)</td>
<td>59 (2.3%)</td>
<td>145 (4.2%)</td>
</tr>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>9054 (97.7%)</td>
<td>2438 (96.5%)</td>
<td>1421 (40.8%)</td>
</tr>
<tr>
<td>Female</td>
<td>210 (2.3%)</td>
<td>88 (3.5%)</td>
<td>2063 (59.2%)</td>
</tr>
</tbody>
</table>

*Seventy-three 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 401 people had a bleeding disorder other than hemophilia or VWD.
Table 2. Sources* of health care reimbursement listed by people enrolled in UDC

<table>
<thead>
<tr>
<th>Reimbursement source</th>
<th>Number</th>
<th>% of Total</th>
<th>Number</th>
<th>% of Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Commercial Insurance</td>
<td>2238</td>
<td>19.0</td>
<td>774</td>
<td>22.2</td>
</tr>
<tr>
<td>Commercial Insurance HMO</td>
<td>2142</td>
<td>18.2</td>
<td>801</td>
<td>23.0</td>
</tr>
<tr>
<td>Commercial Insurance PPO</td>
<td>2435</td>
<td>20.7</td>
<td>755</td>
<td>21.7</td>
</tr>
<tr>
<td>Medicare</td>
<td>1046</td>
<td>8.9</td>
<td>176</td>
<td>5.1</td>
</tr>
<tr>
<td>Medicare HMO</td>
<td>89</td>
<td>0.8</td>
<td>32</td>
<td>0.9</td>
</tr>
<tr>
<td>Medicaid</td>
<td>2446</td>
<td>20.8</td>
<td>453</td>
<td>13.0</td>
</tr>
<tr>
<td>Medicaid HMO</td>
<td>622</td>
<td>5.3</td>
<td>256</td>
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</tr>
<tr>
<td>CHAMPUS</td>
<td>85</td>
<td>0.7</td>
<td>45</td>
<td>1.3</td>
</tr>
<tr>
<td>State high risk plan</td>
<td>452</td>
<td>3.8</td>
<td>67</td>
<td>1.9</td>
</tr>
<tr>
<td>Other</td>
<td>1566</td>
<td>13.3</td>
<td>440</td>
<td>12.6</td>
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<tr>
<td>Uninsured</td>
<td>503</td>
<td>4.3</td>
<td>127</td>
<td>3.7</td>
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</table>

*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

<table>
<thead>
<tr>
<th>Disease</th>
<th>Number</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Hemophilia</strong></td>
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<td></td>
</tr>
<tr>
<td>Mild</td>
<td>3041</td>
<td>25.8</td>
</tr>
<tr>
<td>Moderate</td>
<td>2683</td>
<td>23.0</td>
</tr>
<tr>
<td>Severe</td>
<td>6066</td>
<td>51.5</td>
</tr>
<tr>
<td><strong>VWD</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Type 1</td>
<td>2501</td>
<td>71.8</td>
</tr>
<tr>
<td>Type 2</td>
<td>370</td>
<td>10.6</td>
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<tr>
<td>Type 3</td>
<td>238</td>
<td>6.8</td>
</tr>
<tr>
<td>Other/Unknown</td>
<td>375</td>
<td>10.8</td>
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</table>
Table 4. Bleeding episodes among people enrolled in UDC by prophylaxis use and disease severity*

<table>
<thead>
<tr>
<th>No Prophylaxis</th>
<th>Hemophilia</th>
<th>VWD</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mild n = 3011</td>
<td>Moderate n = 2373</td>
</tr>
<tr>
<td></td>
<td>Type 1 n = 2486</td>
<td>Type 2 n = 370</td>
</tr>
<tr>
<td>Bleeding site</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Joint*</td>
<td>0.6 (±2.6)</td>
<td>3.1 (±8.0)</td>
</tr>
<tr>
<td>Muscle**</td>
<td>0.3 (±1.1)</td>
<td>0.9 (±3.1)</td>
</tr>
<tr>
<td>Other**</td>
<td>0.9 (±4.2)</td>
<td>1.5 (±7.4)</td>
</tr>
<tr>
<td>All sites</td>
<td>Mean (±SD) 1.8 (±5.6)</td>
<td>5.5 (±12.7)</td>
</tr>
<tr>
<td></td>
<td>Median 0</td>
<td>2</td>
</tr>
</tbody>
</table>

| Prophylaxis | Hemophilia |                |
|            | Moderate n =292 | Severe n=2057 |
| Bleeding Site | | |
| Joint**     | 3.4 (±5.8) | 3.1 (±7.2) |
| Muscle**    | 0.8 (±3.2) | 0.9 (±4.6) |
| Other**     | 1.9 (±7.6) | 1.2 (±4.3) |
| All sites   | Mean (±SD) 6.0 (±10.0) | 5.2( ±10.7) |
|             | Median 3 | 2 |

*Includes people 2 years of age or older
**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*

<table>
<thead>
<tr>
<th>Risk Factors for liver disease</th>
<th>Hemophilia (n = 11719)</th>
<th>% of Total</th>
<th>VWD (n = 3482)</th>
<th>% of Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Past/present hepatitis B virus infection</td>
<td>656</td>
<td>5.6</td>
<td>28</td>
<td>0.8</td>
</tr>
<tr>
<td>Past/present hepatitis C virus infection</td>
<td>1435</td>
<td>12.3</td>
<td>76</td>
<td>2.2</td>
</tr>
<tr>
<td>History of alcohol abuse</td>
<td>476</td>
<td>4.1</td>
<td>19</td>
<td>0.6</td>
</tr>
<tr>
<td>Other</td>
<td>169</td>
<td>1.4</td>
<td>18</td>
<td>0.5</td>
</tr>
<tr>
<td>None</td>
<td>10084</td>
<td>86.0</td>
<td>3395</td>
<td>97.5</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Signs or symptoms of liver disease</th>
<th>Hemophilia (n = 11719)</th>
<th>% of Total</th>
<th>VWD (n = 3482)</th>
<th>% of Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jaundice</td>
<td>78</td>
<td>0.7</td>
<td>3</td>
<td>0.1</td>
</tr>
<tr>
<td>Ascites</td>
<td>70</td>
<td>0.6</td>
<td>5</td>
<td>0.1</td>
</tr>
<tr>
<td>Varices</td>
<td>61</td>
<td>0.5</td>
<td>7</td>
<td>0.2</td>
</tr>
<tr>
<td>Other</td>
<td>98</td>
<td>0.8</td>
<td>11</td>
<td>0.3</td>
</tr>
<tr>
<td>None</td>
<td>11500</td>
<td>98.1</td>
<td>3460</td>
<td>99.4</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Laboratory markers of liver disease</th>
<th>Hemophilia (n = 11719)</th>
<th>% of Total</th>
<th>VWD (n = 3482)</th>
<th>% of Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chronically elevated ALT/AST levels</td>
<td>1557</td>
<td>13.3</td>
<td>65</td>
<td>1.9</td>
</tr>
<tr>
<td>Elevated prothrombin time in the last year</td>
<td>231</td>
<td>2.0</td>
<td>62</td>
<td>1.8</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Therapy for chronic viral hepatitis</th>
<th>Hemophilia (n = 11719)</th>
<th>% of Total</th>
<th>VWD (n = 3482)</th>
<th>% of Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Any therapy</td>
<td>873</td>
<td>7.4</td>
<td>43</td>
<td>1.2</td>
</tr>
<tr>
<td>Successful therapy</td>
<td>271</td>
<td>31.3**</td>
<td>13</td>
<td>31.0**</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Intravenous access devices (IVAD)</th>
<th>Hemophilia (n = 11719)</th>
<th>% of Total</th>
<th>VWD (n = 3482)</th>
<th>% of Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Used an IVAD in the last year</td>
<td>1293</td>
<td>11.0</td>
<td>74</td>
<td>2.1</td>
</tr>
<tr>
<td>IVAD infection in the last year</td>
<td>147</td>
<td>11.4*</td>
<td>5</td>
<td>6.8*</td>
</tr>
</tbody>
</table>

*Includes people 2 years of age or older
**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

<table>
<thead>
<tr>
<th>Treatment</th>
<th>Mild</th>
<th>Moderate</th>
<th>Severe</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number</td>
<td>Percent</td>
<td>Number</td>
</tr>
<tr>
<td>Episodic care</td>
<td>2993</td>
<td>98.4</td>
<td>2286</td>
</tr>
<tr>
<td>Intermittent Prophylaxis</td>
<td>26</td>
<td>0.9</td>
<td>94</td>
</tr>
<tr>
<td>Continuous Prophylaxis*</td>
<td>21</td>
<td>0.7</td>
<td>291</td>
</tr>
<tr>
<td><strong>Total number</strong></td>
<td><strong>3041</strong></td>
<td></td>
<td><strong>2683</strong></td>
</tr>
</tbody>
</table>

*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

<table>
<thead>
<tr>
<th>Severity</th>
<th>Hemophilia A</th>
<th>Hemophilia B</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number</td>
<td>Low titer</td>
</tr>
<tr>
<td>Mild</td>
<td>2372</td>
<td>23 (1.0%)</td>
</tr>
<tr>
<td>Moderate</td>
<td>1788</td>
<td>59 (3.3%)</td>
</tr>
<tr>
<td>Severe</td>
<td>5104</td>
<td>310 (6.1%)</td>
</tr>
</tbody>
</table>

*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

<table>
<thead>
<tr>
<th>Treatment product</th>
<th>Hemophilia A n = 9264</th>
<th>Hemophilia B n = 2526</th>
<th>VWD n = 3484</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recombinant factor</td>
<td>5876 63.4</td>
<td>1420 56.2</td>
<td>11 0.3</td>
</tr>
<tr>
<td>Monclonal factor VIII</td>
<td>1443 15.6</td>
<td>3 0.1</td>
<td>5 0.1</td>
</tr>
<tr>
<td>Other human factor VIII</td>
<td>191 2.1</td>
<td>2 0.1</td>
<td>641 18.4</td>
</tr>
<tr>
<td>Porcine factor VIII</td>
<td>12 0.1</td>
<td>0 --</td>
<td>0 --</td>
</tr>
<tr>
<td>Purified factor IX</td>
<td>8 0.1</td>
<td>483 19.1</td>
<td>0 --</td>
</tr>
<tr>
<td>Prothrombin complex</td>
<td>29 0.3</td>
<td>25 1.0</td>
<td>0 --</td>
</tr>
<tr>
<td>Activated prothrombin complex</td>
<td>299 3.2</td>
<td>22 0.9</td>
<td>0 --</td>
</tr>
<tr>
<td>Cryoprecipitate or FFP</td>
<td>55 0.6</td>
<td>10 0.4</td>
<td>52 1.5</td>
</tr>
<tr>
<td>Desmopressin</td>
<td>766 8.3</td>
<td>8 0.3</td>
<td>1416 40.6</td>
</tr>
<tr>
<td>None used</td>
<td>1108 12.0</td>
<td>601 23.8</td>
<td>1383 39.7</td>
</tr>
</tbody>
</table>

*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

<table>
<thead>
<tr>
<th>Treatment</th>
<th>Total using any product*</th>
<th>Number on Multiple Products (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Episodic Care</td>
<td>6942</td>
<td>1655 (23.8)</td>
</tr>
<tr>
<td>Intermittent Prophylaxis</td>
<td>594</td>
<td>133 (22.4)</td>
</tr>
<tr>
<td>Continuous Prophylaxis</td>
<td>2362</td>
<td>577 (24.4)</td>
</tr>
</tbody>
</table>

*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

<table>
<thead>
<tr>
<th>Severity</th>
<th>Total using any product</th>
<th>Number on Multiple Products (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild</td>
<td>1914</td>
<td>561 (29.3)</td>
</tr>
<tr>
<td>Moderate</td>
<td>2187</td>
<td>523 (23.9)</td>
</tr>
<tr>
<td>Severe</td>
<td>5915</td>
<td>1325 (22.4)</td>
</tr>
<tr>
<td>ALL</td>
<td>10016</td>
<td>2409 (24.1)</td>
</tr>
</tbody>
</table>
Table 11. Prevalence of multiple factor product use among people with hemophilia by current inhibitor titer*

<table>
<thead>
<tr>
<th>Hemophilia A</th>
<th>Total using any product</th>
<th>Number on Multiple Products (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Negative</td>
<td>5261</td>
<td>1306 (24.8)</td>
</tr>
<tr>
<td>Low Titer</td>
<td>377</td>
<td>112 (29.7)</td>
</tr>
<tr>
<td>High Titer</td>
<td>284</td>
<td>122 (43.0)</td>
</tr>
<tr>
<td>Missing</td>
<td>2177</td>
<td>589 (27.1)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Hemophilia B</th>
<th>Total using any product</th>
<th>Number on Multiple Products (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Negative</td>
<td>1210</td>
<td>152 (12.6)</td>
</tr>
<tr>
<td>Low Titer</td>
<td>23</td>
<td>3 (13.0)</td>
</tr>
<tr>
<td>High Titer</td>
<td>31</td>
<td>11 (35.5)</td>
</tr>
<tr>
<td>Missing</td>
<td>653</td>
<td>114 (17.5)</td>
</tr>
</tbody>
</table>

* 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 2004

*Occurrence since last annual visit
Figure 11. Prevalence of intra-cranial hemorrhage in people with hemophilia B by severity, May 1998 - December 2004

*Occurrence since last annual visit

Table 12. Joint complications among people enrolled in UDC*

<table>
<thead>
<tr>
<th></th>
<th>Hemophilia</th>
<th>VWD</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mild n(%)</td>
<td>Moderate n(%)</td>
</tr>
<tr>
<td>Target joint **</td>
<td>153 (5.0)</td>
<td>501 (18.8)</td>
</tr>
<tr>
<td>Invasive procedure</td>
<td>70 (2.3)</td>
<td>84 (3.2)</td>
</tr>
<tr>
<td>Joint infection</td>
<td>23 (0.8)</td>
<td>16 (0.6)</td>
</tr>
<tr>
<td>Used cane</td>
<td>380 (12.5)</td>
<td>594 (22.3)</td>
</tr>
<tr>
<td>Used wheelchair</td>
<td>86 (2.8)</td>
<td>127 (4.8)</td>
</tr>
<tr>
<td>Any activity restriction</td>
<td>499 (16.5)</td>
<td>745 (28.0)</td>
</tr>
</tbody>
</table>

*Includes people 2 years of age or older
**Please see Technical Notes (page33) for the definition of a target joint
Table 13. Joint limitations among people enrolled in UDC*

<table>
<thead>
<tr>
<th>Hemophilia</th>
<th>Mild</th>
<th>Moderate</th>
<th>Severe</th>
<th>Type 1</th>
<th>Type 2</th>
<th>Type 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of patients</td>
<td>2763</td>
<td>2401</td>
<td>5166</td>
<td>2324</td>
<td>344</td>
<td>214</td>
</tr>
<tr>
<td>Mean indicator** value</td>
<td>55.1</td>
<td>87.1</td>
<td>148.6</td>
<td>17.9</td>
<td>27.9</td>
<td>70.5</td>
</tr>
<tr>
<td>Standard deviation</td>
<td>104.5</td>
<td>151.9</td>
<td>209.2</td>
<td>88.5</td>
<td>80.5</td>
<td>116.7</td>
</tr>
</tbody>
</table>

* Includes people 2 years of age or older
**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 over time among people with hemophilia enrolled in UDC*

* Includes people 2 years of age or older
Figure 13. Regional distribution of natural or acquired immunity to hepatitis A virus among people with hemophilia enrolled in UDC*

* Includes people 2 years of age or older

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

* Includes people 2 years of age or older
**Figure 15.** Prevalence of natural or acquired immunity to hepatitis B virus over time among people with hemophilia enrolled in UDC*

* Includes people 2 years of age or older

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

* Includes people 2 years of age or older
Figure 17. Prevalence of natural or acquired immunity to hepatitis B virus over time among people with VWD enrolled in UDC*

* Includes people 2 years of age or older

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 infected with hepatitis C enrolled in UDC*

* Includes people 2 years of age or older

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

<table>
<thead>
<tr>
<th>Level of Severity</th>
<th>Age Group (years)</th>
<th>Total</th>
<th>N (%)</th>
<th>Total</th>
<th>N (%)</th>
<th>Total</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild</td>
<td>&lt;2</td>
<td>7</td>
<td>0 (0.0)</td>
<td>11</td>
<td>1 (9.1)</td>
<td>34</td>
<td>6 (17.7)</td>
</tr>
<tr>
<td></td>
<td>2-5</td>
<td>181</td>
<td>3 (1.7)</td>
<td>171</td>
<td>24 (14.0)</td>
<td>615</td>
<td>328 (53.3)</td>
</tr>
<tr>
<td></td>
<td>6-10</td>
<td>320</td>
<td>4 (1.3)</td>
<td>298</td>
<td>62 (20.8)</td>
<td>759</td>
<td>483 (63.6)</td>
</tr>
<tr>
<td></td>
<td>11-15</td>
<td>370</td>
<td>4 (1.1)</td>
<td>299</td>
<td>78 (26.1)</td>
<td>836</td>
<td>469 (56.1)</td>
</tr>
<tr>
<td></td>
<td>16-20</td>
<td>347</td>
<td>1 (0.3)</td>
<td>275</td>
<td>42 (15.3)</td>
<td>773</td>
<td>278 (36.0)</td>
</tr>
<tr>
<td></td>
<td>21-25</td>
<td>175</td>
<td>0 (0.0)</td>
<td>148</td>
<td>9 (6.1)</td>
<td>537</td>
<td>105 (19.6)</td>
</tr>
<tr>
<td></td>
<td>31-30</td>
<td>119</td>
<td>2 (1.7)</td>
<td>93</td>
<td>2 (2.2)</td>
<td>315</td>
<td>24 (7.6)</td>
</tr>
<tr>
<td></td>
<td>31+</td>
<td>853</td>
<td>2 (0.2)</td>
<td>493</td>
<td>22 (4.5)</td>
<td>1235</td>
<td>112 (9.1)</td>
</tr>
</tbody>
</table>

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

<table>
<thead>
<tr>
<th>Level of Severity</th>
<th>Age Group (years)</th>
<th>Total</th>
<th>N (%)</th>
<th>Total</th>
<th>N (%)</th>
<th>Total</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild</td>
<td>&lt;2</td>
<td>2</td>
<td>0 (0.0)</td>
<td>7</td>
<td>1 (14.3)</td>
<td>10</td>
<td>3 (30.0)</td>
</tr>
<tr>
<td></td>
<td>2-5</td>
<td>52</td>
<td>0 (0.0)</td>
<td>87</td>
<td>8 (9.2)</td>
<td>97</td>
<td>45 (46.4)</td>
</tr>
<tr>
<td></td>
<td>6-10</td>
<td>84</td>
<td>2 (2.4)</td>
<td>132</td>
<td>14 (10.6)</td>
<td>142</td>
<td>74 (52.1)</td>
</tr>
<tr>
<td></td>
<td>11-15</td>
<td>111</td>
<td>1 (0.9)</td>
<td>149</td>
<td>16 (10.7)</td>
<td>139</td>
<td>56 (40.3)</td>
</tr>
<tr>
<td></td>
<td>16-20</td>
<td>76</td>
<td>0 (0.0)</td>
<td>116</td>
<td>8 (6.9)</td>
<td>134</td>
<td>31 (23.1)</td>
</tr>
<tr>
<td></td>
<td>21-25</td>
<td>38</td>
<td>0 (0.0)</td>
<td>71</td>
<td>0 (0.0)</td>
<td>81</td>
<td>15 (18.5)</td>
</tr>
<tr>
<td></td>
<td>31-30</td>
<td>32</td>
<td>1 (3.1)</td>
<td>53</td>
<td>3 (5.7)</td>
<td>58</td>
<td>8 (13.8)</td>
</tr>
<tr>
<td></td>
<td>31+</td>
<td>274</td>
<td>1 (0.4)</td>
<td>280</td>
<td>4 (1.4)</td>
<td>301</td>
<td>29 (9.6)</td>
</tr>
</tbody>
</table>
Table 16. Prevalence of overweight and obesity among UDC participants and the US population

**Overweight**

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Hemophilia</th>
<th>VWD</th>
<th>US Population*</th>
</tr>
</thead>
<tbody>
<tr>
<td>2-12</td>
<td>20.6%</td>
<td>22.1%</td>
<td>13.7%</td>
</tr>
<tr>
<td>13-19</td>
<td>20.8%</td>
<td>21.1%</td>
<td>11.5%</td>
</tr>
<tr>
<td>20+</td>
<td>34.5%</td>
<td>30.1%</td>
<td>32.6%</td>
</tr>
</tbody>
</table>

**Obese**

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Hemophilia</th>
<th>VWD</th>
<th>US Population*</th>
</tr>
</thead>
<tbody>
<tr>
<td>20+</td>
<td>23.5%</td>
<td>33.0%</td>
<td>22.3%</td>
</tr>
</tbody>
</table>

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

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

* Includes people 2 years of age or older

**Proportion of people who are obese with VWD is significantly higher than the proportion of people with hemophilia who are obese (p ≥0.05).
Table 17. Prevalence of overweight and obesity among UDC participants by hemophilia severity and VWD type*

<table>
<thead>
<tr>
<th>Hemophilia</th>
<th>Overweight (all ages)</th>
<th>Obese (age 20+)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild</td>
<td>29.2%</td>
<td>29.2%</td>
</tr>
<tr>
<td>Moderate</td>
<td>29.0%</td>
<td>25.8%</td>
</tr>
<tr>
<td>Severe</td>
<td>25.0%</td>
<td>19.3%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>VWD</th>
<th>Overweight (all ages)</th>
<th>Obese (age 20+)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Type 1</td>
<td>24.8%</td>
<td>33.8%</td>
</tr>
<tr>
<td>Type 2</td>
<td>25.8%</td>
<td>27.1%</td>
</tr>
<tr>
<td>Type 3</td>
<td>27.5%</td>
<td>32.1%</td>
</tr>
<tr>
<td>Other/Unknown</td>
<td>24.0%</td>
<td>35.8%</td>
</tr>
</tbody>
</table>

* Includes people 2 years of age or older

Figure 22. Prevalence of overweight and obesity among people in UDC (age ≥20) by region
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 ≥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 providers.
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
We thank the Regional Coordinators 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
Yale University School of Medicine
New Haven, CT
Maine Medical Center
Scarborough, ME
Dartmouth-Hitchcock Hemophilia Center
Lebanon, NH
Rhode Island Hospital
Providence, RI
Vermont Regional Hemophilia Center
Burlington, VT
UCONN Hemophilia Treatment Center
Farmington, CT
Boston Hemophilia Center- Children’s Hospital
Boston, MA
Boston Hemophilia Center- Brigham and Women’s
Boston, MA

Region II
Mariam Voutsis
Weill Medical College of Cornell University
New York, NY
Puerto Rico Hemophilia Treatment Center
San Juan, PR
UMDNJ-Robert Wood Johnson University Hospital
New Brunswick, NJ
St. Michael’s Medical Center
Newark, NJ
Mary M. Gooley Hemophilia Center, Inc.
Rochester, NY
SUNY Upstate Medical University-Adult Program
Syracuse, NY
SUNY Upstate Medical University-Pediatric Program
Syracuse, NY
Hemophilia Center of Western New York – Adult
Buffalo, NY

Region III
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Children’s Hospital of Philadelphia
Philadelphia, PA
Children’s National 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
Christian 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

The Regional Comprehensive Hemophilia & von Willebrand Treatment Center
Albany, NY
UHSH Blood Disorder Center
Johnson City, NY
Long Island Jewish Medical Center
New Hyde Park, NY
Mount Sinai School of Medicine
New York, NY
Hemophilia Center of Western New York – Pediatric
Buffalo, NY
Newark Beth Israel Medical Center
Newark, NJ
Charleston Area Medical Center  
Charleston, WV
Johns Hopkins University Medical Center  
Baltimore, MD
Children’s Hospital of Philadelphia Specialty Center  
Voorhees, NJ
Penn Comprehensive Hemophilia Program  
Philadelphia, PA
University of Virginia Hospital Adult Hemophilia Program  
Charlottesville, VA

Region IV-N  
Steve Humes, M.P.H.  
Wake Forest University School of Medicine  
Winston-Salem, NC
Norton Kosair Children’s Medical Center  
Louisville, KY
Brown Cancer Center  
Louisville, KY
University of Kentucky Hemophilia Treatment 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
St. Jude Research Hospital  
Memphis, TN
University of North Carolina at Chapel Hill  
Chapel Hill, NC

Region IV-S  
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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

Region V-E  
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Children’s Hospital of Michigan  
Detroit, MI
Henry Ford Hospital Adult Hemophilia and Thrombosis Treatment Center  
Detroit, MI
Munson Medical Center  
Traverse City, MI
West Michigan Pediatric at Bronson  
Kalamazoo, MI
Hemophilia Clinic of West Michigan Cancer Center  
Kalamazoo, MI
Eastern Michigan Hemophilia Treatment Center  
Flint, MI
DeVos Children’s Hospital
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
Forum Health, Youngstown Hemophilia Center
Youngstown, 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 Center for Bleeding Disorders & Clotting Disorders
East Lansing, MI
UHHS Cleveland
Cleveland, OH
Children’s Hospital Medical Center of Akron
Akron, OH
DMC Karmanos Cancer Institute
Detroit, MI
University of Michigan Hemophilia and Coagulation Disorders
Ann Arbor, MI

Region V-W
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Northwestern University
Chicago, IL
Cook County Hospital (Adult)
Chicago, IL
Children’s Memorial Hospital
Chicago, IL
Comprehensive Bleeding Disorders Center
Peoria, IL
Fairview University Hemophilia and Thrombosis Center
Minneapolis, MN
Mayo Comprehensive Hemophilia Center
Rochester, MN

MeritCare Hospital DBA Roger Maris Cancer Center
Fargo, ND
Hemophilia Outreach Centre
Green Bay, WI
Gundersen Clinic
LaCrosse, WI
American Red Cross-Badger Center for Bleeding Disorders
Madison, WI
Sacred Heart Hospital
Eau Claire, 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
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Louisiana Center for Bleeding and Clotting Disorders
New Orleans, LA
Arkansas Center for Bleeding Disorders
Little Rock, AR
Oklahoma Center for Bleeding Disorders
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

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Kansas City Regional Hemophilia Center
Kansas City, MO
Hemophilia/AIDS Treatment Center at St. Louis
University, Dept. of Pediatrics
St. Louis, MO
Center for Bleeding and Thrombotic Disorders
St. Louis, MO
Hemophilia Treatment Center
Columbia, MO
Nebraska Regional Hemophilia Treatment Center
Omaha, NE

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Aurora, CO
Ted R. Montoya Hemophilia Center
Albuquerque, NM
Mountain States Regional Hemophilia Center - Tucson
Tucson, AZ
Phoenix Children's Hospital
Phoenix, AZ
Mountain States Regional Hemophilia Center - Utah
Salt Lake City, UT

Region IX
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Children's Hospital of Los Angeles
Los Angeles, CA
University of California, San Diego
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
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
Puget Sound Blood Center & Program
Seattle, WA
Oregon Hemophilia Treatment Center
Portland, OR
Alaska Hemophilia Program
Anchorage, AK
Idaho Regional Hemophilia Center
Boise, ID
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Hemophilia Treatment Center Regions

*Location of regional core center.

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