UDC
The Universal Data Collection Program
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Report on the Universal Data Collection Program

A special report on children under two years of age in UDC

Includes data collected from April 2003 through September 2005

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

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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 males and females. Although the prevalence of this disease is not precisely known, it is estimated that between one and two percent of the population are affected. There are different types and severity of VWD. Symptoms include heavy or prolonged menstrual bleeding, easy bruising, frequent or prolonged nosebleeds, and prolonged bleeding following surgery, dental work, childbirth, or injury.

Hemophilia is caused by a defect in the gene located on the X chromosome that contains the genetic code for one of the clotting factor proteins necessary for normal blood clotting. A deficiency of factor VIII is referred to as hemophilia A or "classic" hemophilia. In contrast, a deficiency of factor IX characterizes hemophilia B, also known as Christmas disease. The defect usually occurs on one of the two female X chromosomes and results in a carrier state. When males have the defect on their only X chromosome, they have the disease. Thus, almost all of the approximately 17,000 people with hemophilia in the United States are male.

People with severe hemophilia can experience serious bleeding into tissues, muscles, joints, and internal organs, often without any obvious trauma. Repeated bleeding into joints without adequate treatment results in crippling chronic joint disease, one of the severe complications of bleeding disorders. In the mid-1970s, treatment for hemophilia was improved through the use of clotting factor concentrates, products made from the plasma of donated blood. However, because blood donations from thousands of donors are pooled together to make these products, many people with bleeding disorders were infected with hepatitis B and C viruses and with human immunodeficiency virus (HIV), the virus that causes AIDS, before the risk of disease transmission in blood products was recognized and prevention measures taken.

In 1975, Congress initiated federal funding to specialized hemophilia treatment centers (HTCs) to provide comprehensive care to people with bleeding disorders. Since 1986, the Centers for Disease Control and Prevention (CDC) has been involved with the hemophilia community through the HTC system, primarily through risk-reduction efforts aimed at preventing secondary infection of family members with HIV.

In 1991, CDC received a request from the National Hemophilia Foundation to expand their collaborative activities within the bleeding disorders community. Meetings with patients and hemophilia care providers were held during 1992 to determine the areas of highest priority. Based on recommendations from these constituents, a congressional mandate was issued to CDC, with the goal of reducing the human suffering and financial burden of bleeding disorders by focusing national emphasis on prevention and early intervention. The issues of greatest concern identified by the bleeding disorders community were: (1) the safety of the blood supply from infectious diseases and (2) the prevention of joint disease.

In response, CDC developed the Universal Data Collection Program (UDC). The purpose of UDC is two-fold: (1) to establish a sensitive blood safety monitoring system

among people with bleeding disorders and (2) to collect a uniform set of clinical outcomes information that can be used to monitor the occurrence of and potential risk factors for infectious diseases and joint complications.

People with bleeding disorders are enrolled in UDC by care providers in each of the nation's 134 federally funded HTCs. As part of the project, a uniform set of clinical data and plasma specimens is collected by HTC staff each year during each participant's annual comprehensive clinic visit. A portion of the plasma specimen is used to perform free screening tests for hepatitis A, B, and C viruses and for HIV. The remainder of the specimen is stored for use as needed in future blood safety investigations.

Enrollment in UDC began in May 1998. Information about eligibility requirements, enrollment procedures, and data collection can be found in the *Technical Notes* of this report. Participating HTCs are listed by region in the *Acknowledgements*. A regional map is included at the end of this report.

The purpose of this surveillance report is to disseminate the information being collected by UDC to public health workers, health educators and planners, other care providers, and patients in the bleeding disorders community. The report contains information about the demographic characteristics of the participants, their blood and factor product use, and the occurrence and treatment of joint and infectious diseases.

We hope that this information will prove useful to those involved in efforts to reduce or prevent the complications of these conditions.

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 is a special report that focuses on data collected from children under two years of age (babies) who have been enrolled through September 2005. Data collection on this group began its pilot phase in April 2003. The data collected on these initial 38 babies is included in this report. The pilot phase ran through April 2004. Official enrollment of babies into UDC began in May 2004 and continues. In this report, data on enrollment and visits (Tables 1 and 2, Figure 1) include all babies seen through September 2005. However, all subsequent tables and graphs describe the hemophilia population only.

Since April, 2003, 220 babies with bleeding disorders have been enrolled and there have been 229 UDC visits.

Tables 1 and 2 show new enrollment in UDC. 211 and 7 babies with hemophilia and VWD respectively have been enrolled. In addition 2 with Factor VII deficiency were also enrolled (data not shown). Enrollment has approximately doubled in each year, with 30 babies in 2003, 55 in 2004, and 133 through September 2005. (Table 1). Table 2 shows that regional enrollment has ranged from 1 in Region VII to as many as 40 babies in Region VIII.

Figure 1 shows the number of babies with a UDC visit in each year through September 2005 according to visit type. The number of babies with a first time UDC visit is much greater than those with a follow-up visit because enrollment and data collection has only recently begun and enough time has not passed to adequately capture return visits. In the UDC population aged 2 years and over, follow-ups visits outnumber first-time visits at a ratio of approximately 3.5 to 1 over time.

The distribution of demographic characteristics is shown in Table 3. Just over half are 1 year or less and all are males. The population distribution by race and ethnicity is similar to that of the general population

Table 4 lists the sources of healthcare reimbursement. About 50% of participants have some form of commercial insurance, about 40-45% have government sponsored coverage, and the remainder have other types of insurance. Only about 3-4% of the participants are uninsured.

Table 5 shows information on birth. Almost two-thirds of the babies were delivered vaginally. Instrumentation during delivery was performed on 7 babies (3.3%). There were 20 pre-term births (defined as less than 37 weeks at birth) and the mean age of these was 34.7 weeks. Vitamin K was administered almost two-thirds of the time. Less than 10% received clotting factor concentrate at birth and then it was given either for prophylaxis or treatment of a bleed. An HTC was contacted before delivery in only 32.5% of the cases.

Diagnostic testing is described in Table 6. 62% of babies enrolled, had hemophilia diagnostic testing performed because the mother was a known carrier or there was a positive family history. In 34% of the babies , a bleeding symptom prompted the diagnostic testing. The mean age of diagnosis was 18 days and almost 70% of the babies were diagnosed before one month of age. Seven babies had prenatal testing performed, and 13.7% of participants had genetic analysis for the hemophilia genetic mutation.

Figure 2 shows the distribution of disease severity. Over half of the babies had severe disease, 27.5% had moderate disease and 16.1% had mild disease.

Table 7 show site of blood draw for factor activity level that determines disease severity. Over 70% had venipuncture as their site of blood draw.

Table 8 shows that the most common type of treatment used for all severity levels of hemophilia was episodic care. As expected, babies with severe disease were the most likely to be on continuous prophylaxis.

The proportion of overall factor product use is shown in Table 9. The majority of babies with hemophilia who require factor infusion are administered recombinant products. About 25% of babies received no product during the year prior to their UDC visit. Also of note is that 8 babies received cryoprecipitate or fresh frozen plasma, products which are not as effective as clotting factor in treating bleeds.

Table 10 illustrates that among the 158 babies receiving factor product, 22.8% are home infused. Of these, two-thirds receive their infusion from a family member.

Data on bleeding are shown in Tables 11. At enrollment, 68.3% of babies had experienced a bleed and the mean age of the first bleed was 28.5 days. In nearly one-third of cases, the first bleed occurred at the site of circumcision. However, the sites with the

most frequent bleeding episodes were the soft tissues (79 participants), followed by oral/nasal sites (57 participants). Three babies had long-term effects due to bleeding including focal neurological deficits, seizure disorder and neuropathy due to compartment syndrome.

Table 12 lists information on head injuries and intracranial hemorrhages. A majority of babies, 162/211 (76.8%) did not experience a head injury since birth or last UDC visit. Of the 49 babies who had a head injury, 31 had one head injury, 11 had two, and 7 had 3 or more. One of the head injuries resulted in a skull fracture. Finally, 14 babies had an intracranial hemorrhage (ICH). The most common site of ICH was subdural (50%), followed by intracerebral (36.7%) and subarachnoid (14.3%). In most cases, ICH was confirmed by computerized tomography and ICH was found to be associated with delivery at birth or spontaneous occurrence in equal proportions.

Table 13 describes Hepatitis B vaccination status and route of administration. More than half of the babies had completed the basic Hepatitis B vaccination series at UDC enrollment and almost a third (29.9%) were currently receiving the series. Route of administration was intramuscular in 23.7% of babies, subcutaneous in 18.5%, and unknown for 52.6%. The high proportion of unknown administration route data reflects the fact that most of the babies do not receive the vaccine in the treatment center and the parents usually do not know this information.

Table 14 describes the use of central venous access devices for clotting factor infusion. At the latest visit, 11.4% of babies had had at least one CVAD placed since birth or the last UDC visit and, of these, 79.1% were ports. Of those with a CVAD, 10 babies had at least one CVAD complication. The most common CVAD complication was infection, which occurred in 8 of the 10 babies with a complication.

Table 15 shows the prevalence of inhibitors among persons with hemophilia under age 2 enrolled in UDC. The majority of inhibitors occurred in babies with hemophilia A and severe disease and most of these inhibitors

Suggested Reading

Centers for Disease Control and Prevention. Prevention of hepatitis A through active or passive immunization. Recommendations of the Advisory Committee on Immunization Practices (ACIP). MMWR 1996;45(No. RR-15):1-30.

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

Table 1. New Enrollment in UDC, April 2003 -September 2005

Month	Hemophilia	VWD
April-Dec 2003	29	1
Jan-Dec 2004	54	1
January 2005	11	0
February 2005	16	0
March 2005	15	0
April 2005	17	1
May 2005	11	2
June 2005	17	1
July 2005	20	0
August 2005	12	0
September 2005	9	1
Total	**211**	**7**

Table 2. Enrollment in UDC by region*, April 2003 - September 2005

Region	Hemophilia	VWD
I	8	0
II	8	0
III	11	1
IV-N	17	1
IV-S	26	0
V-E	37	2
V-W	16	1
VI	19	1
VII	1	0
VIII	40	1
IX	21	0
X	7	0
Total	**211**	**7**

*See map (page 27) for regional designations.

Figure 1. UDC visits by year, April 2003-September 2005

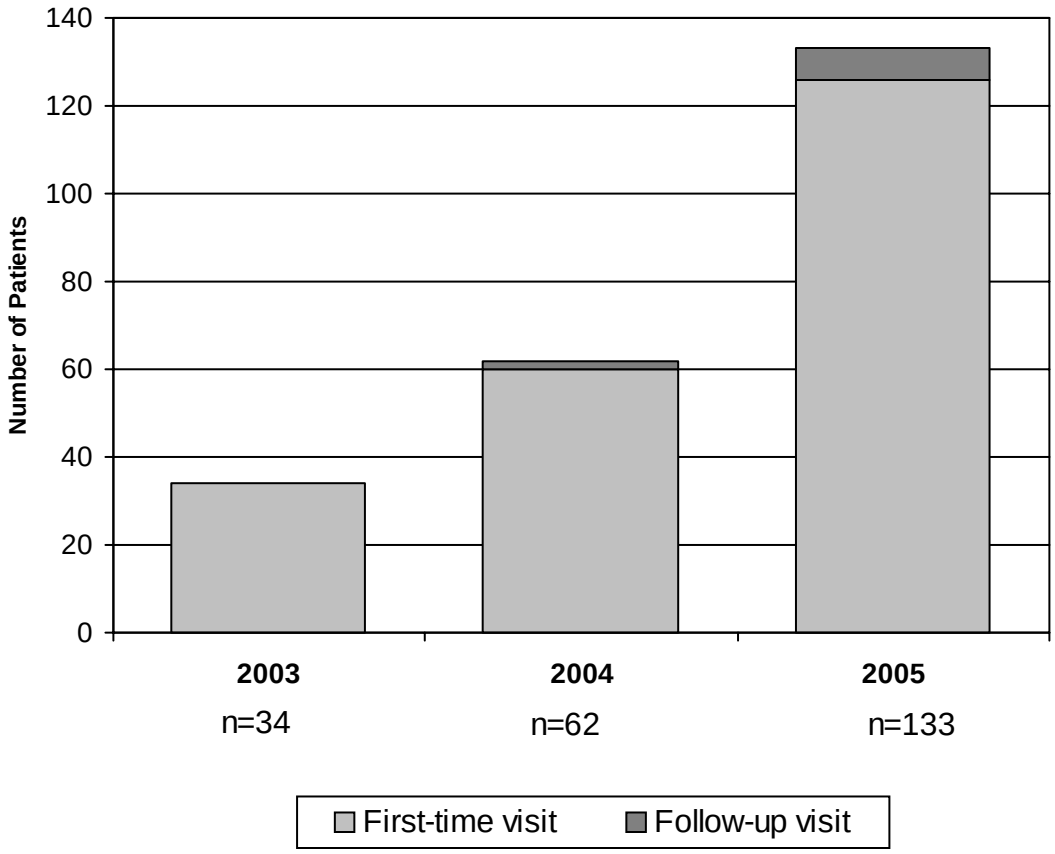

Table 3. Demographic characteristics of children with hemophilia* < 2 years of age enrolled in UDC

	Hemophilia			
	A (n =158)		B (n=53)	
Characteristic	Number	Percent	Number	Percent
Age Group (months)				
0-3	22	13.9	7	13.2
4-6	20	12.7	7	13.2
7-9	17	10.8	3	5.7
10-12	23	14.6	8	15.1
13-15	23	14.6	9	17.0
16-18	18	11.4	5	9.4
19-24	35	22.2	14	26.4
Race/Ethnicity				
White	95	60.1	37	69.8
African American	19	12.0	2	3.8
Hispanic ,	31	19.6	8	15.1
Asian/Pacific Islander	4	2.5	1	1.9
Native American	2	1.3	0	0.0
Other	7	4.4	5	9.4
Sex				
Male	158	100	53	100
Female	0	--	0	--

*One person was reported to have both hemophilia and VWD (this person is included in analyses as a hemophilia patient only and not as a VWD patient). A total of 2 persons had Factor VII deficiency.

Table 4. Sources* of health care reimbursement listed by children with hemophilia <2 years of age enrolled in UDC

Reinbursement Source	Number (n=211)	Percent of Total
Commercial Insurance	29	13.7
Commercial Insurance HMO	35	16.6
Commercial Insurance PPO	41	19.4
Medicare	2	1.0
Medicare HMO	0	--
Medicaid	51	24.2
Medicaid HMO	21	10.0
CHAMPUS	8	3.8
State high risk plan	7	3.3
Other	25	11.9
Uninsured	7	3.3

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

Table 5. Birth Information of children with hemophilia < 2 years of age enrolled in UDC

		Number	% of Total
Delivery Method*			
	Vaginal	138	65.4
	Elective C-Section	40	19.0
	Non-elective C-Section	28	13.3
	Unknown	3	1.4
	Other	1	0.5
Instrumentation during delivery			
	Forceps	1	0.5
	Vacuum	6	2.8
Pre-term birth (<37 weeks) *(Mean age of pre-term infants=34.7)*		20	9.5
Vitamin K administered at birth			
	Yes	133	63.3
	No	19	9.1
	Unknown	59	27.6
Clotting Factor concentrate given at birth			
	Yes	16	7.6
	No	192	91.4
	Unknown	3	1.0
If yes, reason**:	Prophylaxis	10	62.5
	Rx of bleed	6	37.5
HTC contacted before delivery			
	Yes	68	32.5
	No	138	66.0
	Unknown	3	1.4

*More than one delivery method may be selected
**Percent is out of total number with clotting factor given

Table 6. Diagnostic testing on children with hemophilia < 2 years of age enrolled in UDC

		Number	% of Total
Reason for diagnostic testing			
	Mother known carrier	86	41.0
	Other family history	45	21.4
	Bleeding symptom	72	34.3
	Unknown	2	0.4
	Other	6	2.9
Age bleeding disorder first diagnosed *(Mean age at diagnosis=18 days)*			
	Pre-natal	6	2.8
	<1 month	147	69.7
	1-6 months	33	15.6
	7-12 months	15	7.1
	12-24 months	10	4.7
Prenatal testing			
	Amniocentesis	6	2.8
	Other	1	0.5
	Unknown	2	0.9
Genetic analysis since birth or last visit			
	Yes	29	13.7
	No	174	82.5
	Missing	8	3.8

Figure 2. Disease severity of children with hemophilia < 2 years of age enrolled in UDC

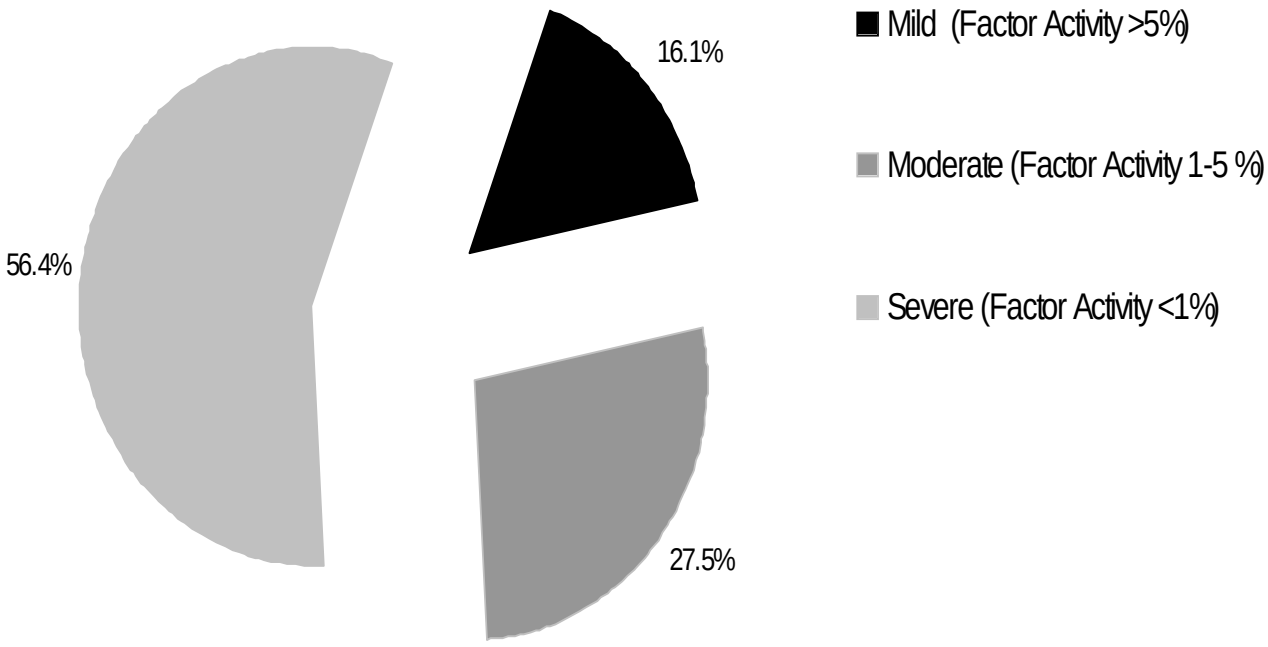

Table 7. Site of blood draw for factor activity level in children with hemophilia < 2 years of age enrolled in UDC

	Number	% of Total
Site of blood draw		
Cord blood	46	22.3
Venipuncture	147	71.4
Unknown	18	6.3

Table 8. Treatment type for children with hemophilia < 2 years of age enrolled in UDC

	Mild		Moderate		Severe	
Treatment	Number	Percent	Number	Percent	Number	Percent
Episodic care	34	100	52	89.7	96	80.7
Continuous Prophylaxis	0	--	5	8.6	18	15.1
Total	**34**		**58**		**119**	

*Prophylaxis is considered continuous when clotting factor is administered on a regular basis to prevent all bleeding and is expected to continue indefinitely.

Table 9. Blood and factor products used* by children with hemophilia <2 years of age enrolled in UDC

	Hemophilia A		Hemophilia B	
Treatment product	Number	Percent	Number	Percent
Recombinant factor	108	68.4	36	67.9
Monclonal factor VIII	0	--	0	--
Other human factor VIII	4	2.5	0	--
Porcine factor VIII	0	--	0	--
Human factor IX	0	--	1	1.9
Prothrombin complex	0	--	0	--
Activated prothrombin complex	4	2.5	0	--
Cryoprecipitate of FFP	6	3.8	2	3.8
Desompressin	1	0.6	0	--
Amicar	19	12.3	9	17.0
None used	39	24.7	14	26.4

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

Table 10. Home factor infusion in children with hemophilia < 2 years of age enrolled in UDC

		Number	Percent
Home infusion (n=158)		36	22.8
Infusion given by:	Family member	24	66.7
	Care provider	15	41.7

*Percent is out of total number of those receiving home infusion. Indivdiuals may have more than one method of home infusion.

Table 11. Bleeding in children with hemophilia <2 years of age enrolled in UDC

	Number	% of Total
History of ever having a bleed		
Yes	144	68.3
No	67	31.7
Mean age of first bleed=28.5 days (unknown for 3 babies)		
Site of first bleed*		
Head (Intracranial/Extracranial)	22	15.3
Oral Mucosa	15	10.4
Circumcision	44	30.6
Joint	7	4.9
Intramuscular injection	4	2.7
Unknown	5	3.5
Other	47	32.6

Bleeds reported since birth or last UDC visit

Site of bleeding	Number
Intracranial Hemorrhage	14
Circumcision	33
Oral/Nasal	57
Venipuncture/Heel Stick/Surgical Site	21
Soft Tissue Hematoma	79
Intramuscular Hematoma	30
Umbilicus	2
Joint	31
Gastrointestinal	7
Genitourinary, renal	2
Pulmonary	1
Long term effects due to bleeding	**3**
Type of effect**:	
Focal Neurological	2
Seizure Disorder	1
Hydrocephaly	0
Neurropathy due to compartment syndrome	1
Paralysis	0

*Percent is out of those who reported ever having a bleed
*More than one long term effect seen in one baby

Table 12. Head injuries and intracranial hemorrhages (ICH) in children with hemophilia <2 years of age enrolled in UDC

		Number	% of Total
Head injuries since birth or last UDC visit			
	> 3	7	3.3
	2	11	5.2
	1	31	14.7
	0	162	76.8
Number of head injuries resulting in skull fracture*		1	2.0
Number of ICH		14	6.6
Site of ICH**			
	Intracerebral	5	36.7
	Subdural	7	50.0
	Subarachnoid	2	14.3
	Epidural	1	7.1
	Intra/periventricular	0	0.0
	Cerebellar	1	7.1
ICH confirmed by**			
	Exam	2	14.3
	Xray	0	0.0
	Ultrasound	0	0.0
	MRI	1	7.1
	CT	12	85.7
	None	0	0.0
	Other	0	0.0
ICH associated with**			
	Delivery	6	42.9
	Trauma	2	14.3
	Thrombocytopenia	0	0.0
	Procedural	1	7.1
	Spontaneous	6	42.9
	Other	0	0.0

*Percent is out of total number with head injuries
** More than one choice is possible and percent is out of total number of ICHs

Table 13. Hepatitis B vaccination in children with hemophilia <2 years of age enrolled in UDC

	Number	% of Total
Status of Hepatitis B vaccination		
Completed basic vaccination series	109	51.7
Receiving basic vaccination series	63	29.9
Never received any doses	15	7.1
Unknown	24	11.4
Route of administration		
Intramuscular	50	23.7
Subcutaneous	39	18.5
Both IM and SQ	11	5.2
Unknown	111	52.6

Table 14. Central venous access devices (CVADs) in children with hemophilia < 2 years of age enrolled in UDC

		Number	% of Total
Babies with at least one CVAD placed		24	11.4
Type of CVAD**	Port	19	79.1
	Catheter	6	25.0
	PICC	2	8.3
Babies with at least one CVAD complication			
Type of complication**	Infection	8	80.0
	Thrombus	0	--
	Mechaincal	3	30.0
	Bleeding	3	30.0
	Other	0	--

*Percent is out of total number of babies with CVADs placed
** Percent is out of total number of babies with complications

Table 15. Prevalence of current inhibitors by titer* among children with hemophilia < 2 years of age enrolled in UDC

	Hemophilia A			Hemophlia B		
Severity	Number	Low titer	High titer	Number	Low titer	High Titer
Mild	29	0	0	5	0	0
Moderate	34	3 (8.8%)	0	24	1 (4.2%)	0
Severe	95	9 (9.5%)	6 (6.3%)	24	1 (4.2%)	1 (4.2%)

* 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.

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) have 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) have 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. However, participants under 2 years of age are encouraged to be evaualated every 6 months until the age of 2, and data are collected during these visits according to guidelines and definitions detailed in surveillance manuals provided to HTC staff by CDC. 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 or baby visit form). For children under the age of two, information about their birth; diagnostic testing; site of blood draw; the type of treatment (episodic vs. prophylactic); the presence and treatment of inhibitors; the number of intracranial bleeding episodes experienced; the type and brand name of all factor concentrates or other treatment products used; and whether or not clotting factor is infused at home is collected. Data are also recorded about the status of vaccination against hepatitis B; and among patients with an intravenous access device, the occurrence of a device-associated infection.

All data collection forms are sent to CDC where they are then key entered into a 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

Blood specimens are not obtained from participants under the age two, thus no laboratory testing is preformed.

Mortality Reporting

Deaths occurring among all HTC patients

(regardless of whether they have been enrolled in UDC) are reported to CDC using a mortality form. Data collected include age at death, sex, race or ethnicity, type and severity of disease, and whether or not blood products had been used during the year prior to death. Additionally, information about the death, including the date, cause (primary and contributing), and whether or not an autopsy was performed, is also collected.

Tabulation and Presentation of Data

Data in this report are provisional. The data represent the most current data available from an on-going surveillance project. Future reports will include expanded data tables to cover subsequent surveillance periods and will provide the results of more detailed analyses of available data and findings from special studies.

Acknowledgements

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Region I
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Worcester, MA
Yale University School of Medicine
New Haven, CT
Maine Medical Center
Scarborough, ME
Dartmouth Hitchcock Hemophilia Center
Lebanon, NH
Rhode Island Hospital
Providence, RI
UCONN Hemophilia Treatment Center
Farmington, CT
Vermont Regional Hemophilia Center
Burlington, VT
Boston Children's Hospital
Boston, MA

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New York, NY
Puerto Rico Hemophilia Treatment Center
San Juan, PR
UMDNJ Robert Wood Johnson University
Hospital, New Brunswick, NJ
St. Michael's Comprehensive Hemophilia
Care Center, Newark, NJ
The Mary M. Gooley Hemophilia Center, Inc.
Rochester, NY
SUNY Health Science Center Adult
Syracuse, NY
SUNY Health Science Center Pediatric
Syracuse, NY
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Buffalo, NY
Hemophilia Center of Western New York -
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Albany, NY
UHSH Blood Disorders Center
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Columbia, SC
University of Tennessee - Memphis
Memphis, TN
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Miami, FL
University of Florida
Gainesville, FL
Children's Healthcare of Atlanta at Scottish Rite
Atlanta, GA
Medical College of Georgia Adult
Augusta, GA
University of Mississippi Medical Center
Jackson, MS
University of Alabama Birmingham Medical Center
Birmingham, AL
Miami Comprehensive Hemophilia Center Adult
Miami, FL
Children's Rehabilitation Services
Mobile, AL
Children's Rehabilitation Services
Birmingham, AL
Emory University Hemophilia Program Office
Atlanta, GA
Children's Rehabilitation Services
Opelika, AL
Children's Rehabilitation Services
Huntsville, AL
Medical College of Georgia Pediatrics
Augusta, GA

Region V-E
Tamara Wood-Lively, M.H.A., J.D.
Children's Hospital of Michigan
Detroit, MI
Munson Medical Center
Traverse City, MI
Hemophilia Clinic of West Michigan Cancer Center
Kalamazoo, MI

Eastern Michigan Hemophilia Treatment Center
Flint, MI
DeVos Children's Hospital at Butterworth
Grand Rapids, MI
Ohio State University Medical Center
Columbus, OH
Cincinnati Children's Hospital Medical Center
Cincinnati, OH
University of Cincinnati Medical Center
Cincinnati, OH
Columbus Children's Hospital
Columbus, OH
Northwest Ohio Hemophilia Treatment Center
Toledo, OH
Dayton Children's Medical Center
Dayton, OH
Indiana Hemophilia and Thrombosis Center
Indianapolis, IN
Michigan State University Comprehensive Center for Bleeding Disorders
East Lansing, MI
Akron Children's Hospital Medical Center
Akron, OH
University of Michigan Hemophilia Treatment Center
Ann Arbor, MI

Region V-W

Mary Anne Schall, R.N., M.S.

Northwestern University
Chicago, IL
Cook County Hospital Adult
Chicago, IL
Children's Memorial Hospital
Chicago, IL
Comprehensive Bleeding Disorders Center
Peoria, IL
Fairview University Medical Center
Minneapolis, MN
Mayo Clinic
Rochester, MN
MeritCare Hospital DBA Roger Maris Cancer Center, Fargo, ND
Hemophilia Outreach Centre
Green Bay, WI
Gunderson Clinic
LaCrosse, WI
American Red Cross Badger Chapter
Madison, WI
Rush Children's Hospital
Chicago, IL
Michael Reese Hospital - Adult
Chicago, IL
South Dakota Children's Specialty Clinics
Sioux Falls, SD
Comprehensive Center for Bleeding Disorders
Milwaukee, WI
Cook County Children's Hospital
Chicago, IL

Region VI

John Drake, R.N., M.S.N.

Gulf States Hemophilia and Thrombosis Center
Houston, TX
Louisiana Comprehensive Hemophilia Center
New Orleans, LA
Hemophilia Center of Arkansas
Little Rock, AR
Oklahoma Comprehensive Hemophilia Treatment Center, Oklahoma City, OK
Fort Worth Comprehensive Hemophilia Center
Ft. Worth, TX
North Texas Comprehensive Hemophilia Center - Adult Program
Dallas, TX
South Texas Comprehensive Hemophilia Center
San Antonio, TX
North Texas Comprehensive Hemophilia Center - Pediatric Program
Dallas, TX

Region VII
Becky Dudley, L.C.S.W.
University of Iowa Hospitals and Clinics
Iowa City, IA
Kansas City Regional Hemophilia Center
Kansas City, MO
Nebraska Regional Hemophilia Treatment Center
Omaha, NE
Missouri/Illinois Regional Hemophilia Center
St. Louis, MO
Center for Bleeding and Thrombotic Disorders
St. Louis, MO
Hemophilia Treatment Center
Columbia, MO

Region VIII
Brenda Riske, M.S., M.B.A., M.P.A.
Mountain States Regional Hemophilia and Thrombosis Center
Denver, CO
Ted R. Montoya Hemophilia Center
Albuquerque, NM
Mountain States Regional Hemophilia Center
Tucson, AZ
Phoenix Children's Hospital
Phoenix, AZ
Mountain States Regional Hemophilia Center - Utah
Salt Lake City, UT

Region IX
Judith Baker, M.H.S.A.
Children's Hospital of Los Angeles
Los Angeles, CA
University of California
San Diego, CA
Lucile Salter Packard Children's Hospital at Stanford
Palo Alto, CA
Alta Bates Medical Center
Berkeley, CA
Hemophilia and Thrombosis Center of Hawaii
Honolulu, HI
University of California at Davis
Sacramento, CA
University of California, San Francisco
San Francisco, CA
Orthopaedic Hospital of Los Angeles
Los Angeles, CA
Children's Hospital, San Diego
San Diego, CA
Children's Hospital of Orange County
Orange, CA
Children's Hospital Oakland
Oakland, CA
City of Hope National Medical Center
Duarte, CA
Guam Comprehensive Hemophilia Care Program, Agana, GU
Valley Children's Hospital
Madera, CA
Hemophilia and Thrombosis Center of Las Vegas
Las Vegas, NV

Region X
Robina Ingram-Rich, R.N., M.S., M.P.H.
Puget Sound Blood Center and Program
Seattle, WA
Oregon Hemophilia Treatment Center
Portland, OR
Alaska Hemophilia Association
Anchorage, AK
Idaho Regional Hemophilia Center
Boise, ID

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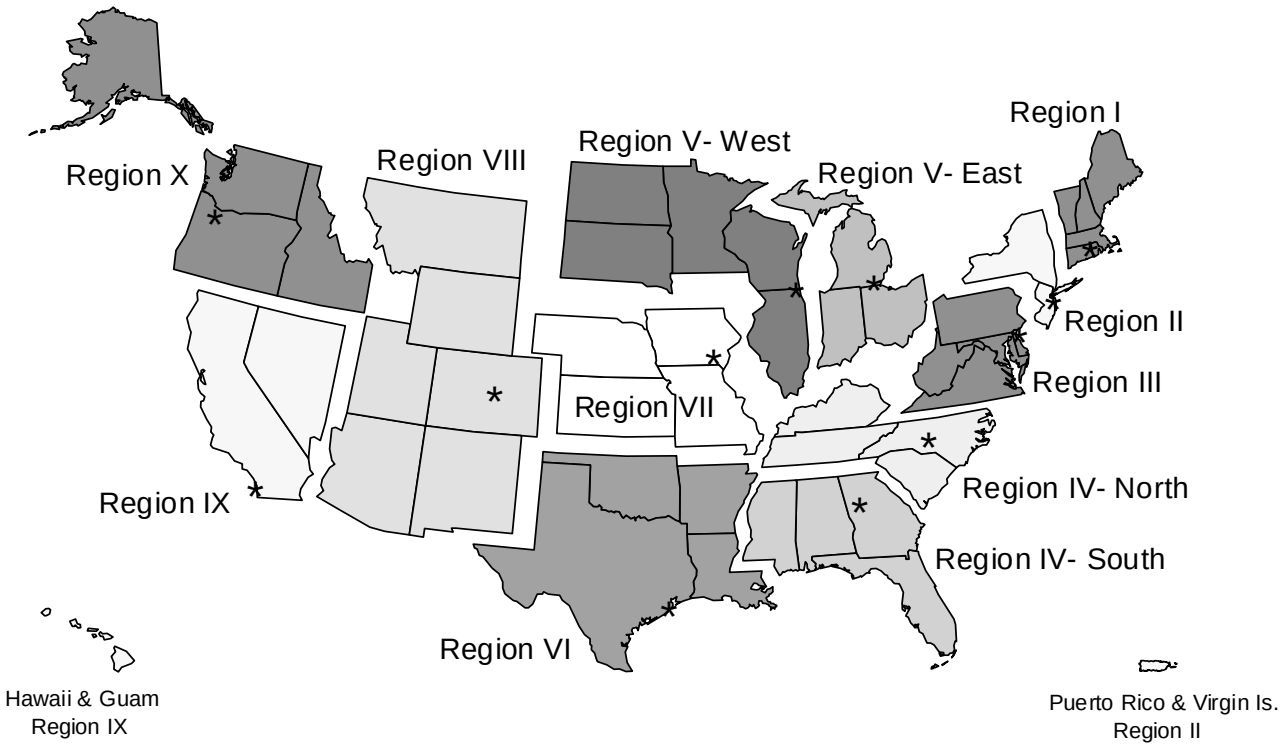
Hemophilia Treatment Center Regions



*Location of regional core center.

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