

ATHN Research Report Brief

ATHNdataset — March 31, 2015



Acknowledgements

This report would not be possible without the dedicated efforts of the ATHN Affiliated Hemophilia Treatment Centers and their patients.

Thank you HTCs!

ATHN gratefully acknowledges its Founding Partner Novo Nordisk and its Industry Consortium for its support.

Industry Visionaries



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NOTE

BLACKENED CELLS INDICATE SMALL SIZED CELLS, DEFINED AS 5 CASES OR LESS

This Research Report is prepared using standardized data collected for the ATHNdataset, a HIPAA compliant limited data set under the stewardship of the American Thrombosis and Hemostasis Network (ATHN).

Data collection is a voluntary effort by clinical teams and data managers at federally funded Hemophilia Treatment Centers (HTCs) across the U.S. The project is open to all ATHN Affiliated centers. Patients are asked to opt-in. At the time of reporting, not all patients receiving care at participating centers have been asked to join, and not all have agreed to participate. The ATHNdataset is extracted from the patient's medical record. It is not the official medical record of the patient. Unknown or missing data indicates that the data was not reported to the ATHNdataset during the reporting period.

Participating centers use reasonable efforts to ensure the accuracy of the data. System design with structured data entry, self-audits and HTC re-use of the information in fulfillment of government funded projects further help to drive quality of the data. However, ATHN makes no warranty or representation that the information will be adequate or satisfactory for particular use.

Finally, if you desire to include any extract of the report in any publication of yours, you must obtain prior written consent to such publication and agree to provide appropriate attribution to ATHN and its Affiliate HTCs.

ATHNdataset

ATHNdataset — Growth of the ATHNdataset

ATHNdataset

PATIENT ACCRUAL OVER TIME (AS OF MARCH 31, 2015)

The ATHNdataset is a HIPAA compliant limited dataset under the stewardship of ATHN.

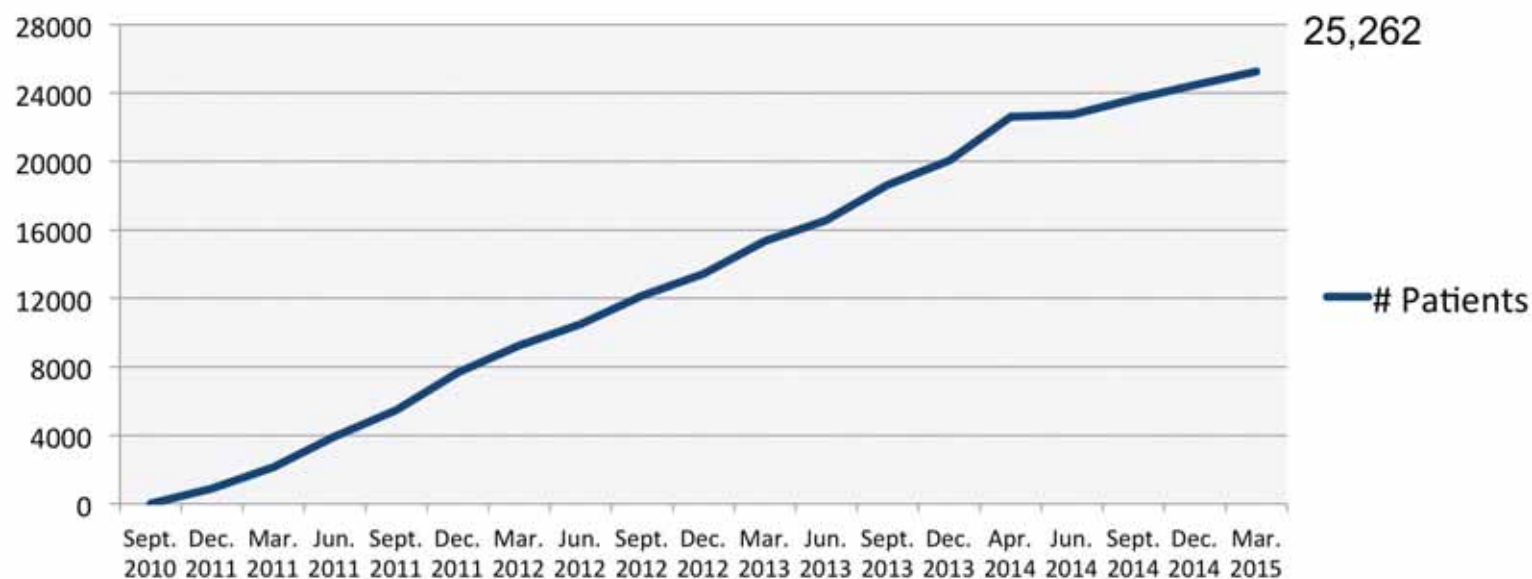
Participating Hemophilia Treatment Centers across the U.S. abstract data from the medical record.

Patients choose to "opt in" by signing a patient authorization.

No special lab tests or clinic visits are required.

Patient identity is protected through the use of a unique system generated identifier.

Since September 2010, the ATHNdataset has grown to include 25,262 patients.



ATHNdataset — Growth of ATHNdataset

ATHNdataset

ATHNdataset (AS OF MARCH 31, 2015) COMPARED TO 2010 HEMOPHILIA DATA SET BEGINNING IN JANUARY 2014, DATA HAS BEEN COLLECTED USING THE NEW ATHN INFRASTRUCTURE.

The ATHNdataset demographics compare favorably to the aggregate Hemophilia Data Set of active patients under care of Hemophilia Treatment Centers.

The 2010 Hemophilia Data Set included 32,612 active patients with Factor VIII Deficiency, Factor IX Deficiency, Von Willebrand Disease and other factor deficiencies.

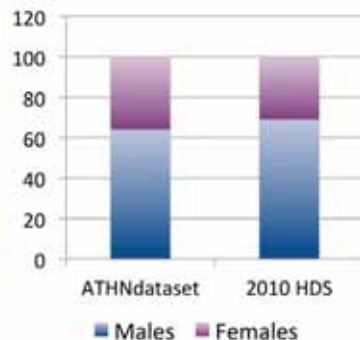
Individual level data are not available through the Hemophilia Data Set.

GENDER COMPARISON

ATHNdataset Gender	# Patients	% Patients
Male	16,182	64%
Female	9,080	36%
Total	25,256	100%

* 5 male to female

2010 HDS Gender	# Patients	% Patients
Male	22,411	69%
Female	10,201	31%
Total	32,612	100%

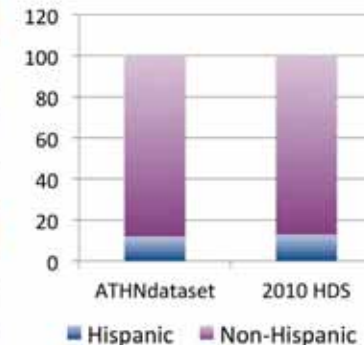


ETHNICITY COMPARISON

ATHNdataset Ethnicity	# Patients	% Patients
Hispanic	3,098	12%
Non Hispanic	21,906	88%
Total	25,004*	100%

* 258 Unknown

2010 HDS Ethnicity	# Patients	% Patients
Hispanic	4,289	12%
Non-Hispanic	28,323	88%
Total	32,612	100%



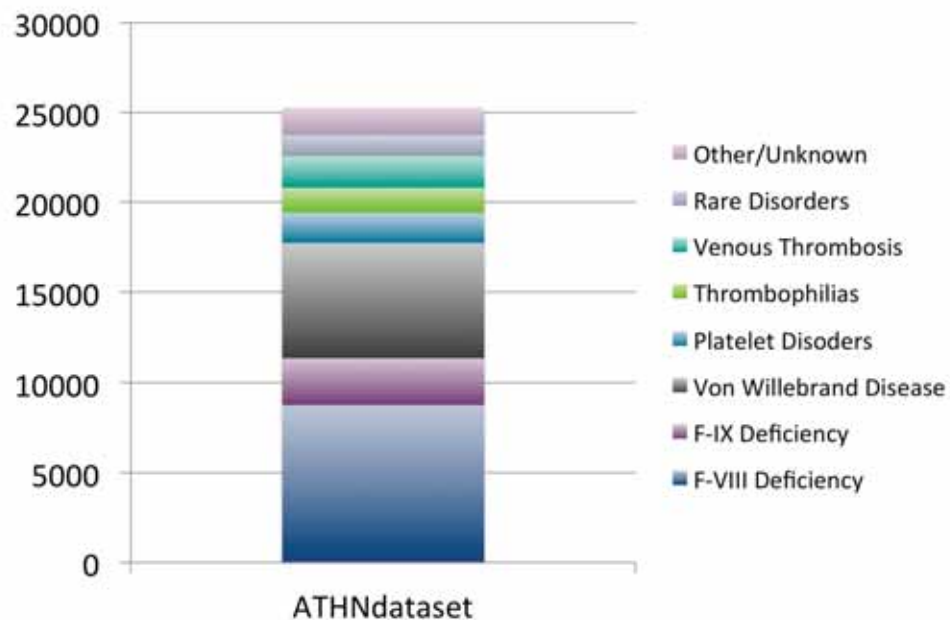
ATHNdataset — Demographic Profile

ATHNdataset	AGE AND SEX BY REGION AND TOTAL U.S. (AS OF MARCH 31, 2015)								
	REGION								TOTAL
	New England	Mid-Atlantic	Southeast	Great Lakes	Northern States	Great Plains	Mountain States	Western States	US
BY SEX									
Female	1205	431	776	4245	491	731	442	759	9080
	36.5%	23.3%	25.1%	49.8%	31.3%	28.5%	24.5%	29.6%	35.9%
Male	2094	1421	2322	4274	1078	1831	1359	1803	16182
	63.5%	76.7%	75.0%	50.2%	68.7%	71.5%	75.5%	70.4%	64.1%
Total	3299	1852	3098	8519	1569	2562	1801	2562	25262
	100%	100%	100%	100%	100%	100%	100%	100%	100%
BY AGE									
0-2 years	79	61	102	232	39	131	56	66	766
	2.4%	3.3%	3.3%	2.7%	2.5%	5.1%	3.1%	2.6%	3.0%
3-12 years	862	413	831	1641	351	827	406	746	6077
	26.1%	22.3%	26.8%	19.3%	22.4%	32.3%	22.5%	29.1%	24.1%
13-18 years	709	317	654	1523	221	588	308	587	4907
	21.5%	17.1%	21.1%	17.9%	14.1%	23.0%	17.1%	22.9%	19.4%
19-29 years	687	375	659	1597	342	401	375	577	5013
	20.8%	20.3%	21.3%	18.8%	21.8%	15.7%	20.8%	22.5%	19.8%
30-49 years	538	376	487	1600	366	314	396	357	4434
	16.3%	20.3%	15.7%	18.8%	23.3%	12.3%	22.0%	13.9%	17.6%
50-74 years	376	285	338	1698	220	276	237	211	3641
	11.4%	15.4%	10.9%	19.9%	14.0%	10.8%	13.2%	8.2%	14.4%
75+ years	48	25	27	228	30	25	23	18	424
	1.5%	1.4%	0.9%	2.7%	1.9%	1.0%	1.3%	0.7%	1.7%
Total	3299	1852	3098	8519	1569	2562	1801	2562	25262
	100%	100%	100%	100%	100%	100%	100%	100%	100%

ATHNdataset Age	Mean	Standard Deviation	Median
	27	20	20

ATHNdataset — Bleeding and Clotting Disorders Within the Population

ATHNdataset	PATIENT AUTHORIZATIONS BY PRIMARY DIAGNOSIS TOTAL U.S. (AS OF MARCH 31, 2015)	
PRIMARY BLEEDING OR CLOTTING DISORDER	TOTAL U.S. ATHNdataset CASES	% ATHNdataset
Factor VIII Deficiency	8766	34.70%
Factor IX Deficiency	2608	10.32%
Von Willebrand Disease	6367	25.20%
Rare Disorders	1174	4.65%
Platelet Disorders	1679	6.65%
Thrombophilias	1392	5.51%
Venous Thrombosis	1758	6.96%
Other/Unknown	1518	6.01%
TOTAL	25262	100.00%



Factor VIII Deficiency

Factor VIII Deficiency — Bleeding Disorder Disease Severity

FACTOR VIII DEFICIENCY		DISEASE SEVERITY BY REGION AND TOTAL U.S. (AS OF MARCH 31, 2015)							
DISEASE SEVERITY	REGION								TOTAL
	New England	Mid-Atlantic	Southeast	Great Lakes	Northern States	Great Plains	Mountain States	Western States	US
Mild	307	205	358	407	170	283	276	343	2349
	27.0%	24.3%	24.0%	31.6%	27.2%	27.6%	28.5%	29.3%	27.5%
Moderate	199	149	292	201	101	164	177	189	1472
	17.5%	17.7%	19.6%	15.6%	16.2%	16.0%	18.3%	16.1%	17.2%
Severe	631	489	843	681	354	580	516	640	4734
	55.5%	58.0%	56.5%	52.8%	56.6%	56.5%	53.3%	54.6%	55.3%
TOTAL	1137	843	1493	1289	625	1027	969	1172	8555
	100%	100%	100%	100%	100%	100%	100%	100%	100%
Unknown Severity	26	54	10	54	10	31	12	14	211
	2.2%	6.0%	0.7%	4.0%	1.6%	2.9%	1.2%	1.2%	2.4%
TOTAL	1163	897	1503	1343	635	1058	981	1186	8766
	100%	100%	100%	100%	100%	100%	100%	100%	100%

Factor VIII Deficiency — HIV and Hepatitis C

FACTOR VIII DEFICIENCY		HIV AND HEPATITIS C (HCV) BY AGE GROUP (AS OF MARCH 31, 2015)						
AGE								TOTAL
HIV CO-MORBIDITY								
	0-2 years	3-12 years	13-18 years	19-29 years	30-49 years	50-74 years	75+ years	US
HIV	0	0		7	359	222		591
	0.0%	0.0%		0.4%	21.4%	22.1%		6.7%
No HIV	320	2282	1408	1981	1317	783	84	8175
	100.0%	100.0%	99.9%	99.7%	78.6%	77.9%	97.7%	93.3%
TOTAL	320	2282	1409	1988	1676	1005	86	8766
	100%	100%	100%	100%	100%	100%	100%	100%
HEPATITIS CO-MORBIDITY								
Hepatitis C	0	0		103	870	554	24	1552
	0.0%	0.0%		5.2%	51.9%	55.1%	27.9%	17.7%
No Hepatitis C	320	2282	1408	1885	806	451	62	7214
	100.0%	100.0%	99.9%	94.8%	48.1%	44.9%	72.1%	82.3%
TOTAL	320	2282	1409	1988	1676	1005	86	8766
	100%	100%	100%	100%	100%	100%	100%	100%

Factor VIII Deficiency – Continuous Prophylaxis (Prescribed)

FACTOR VIII DEFICIENCY		PROPHYLAXIS PRESCRIBED FOR PATIENTS BY BLEEDING DISORDER DISEASE SEVERITY AND AGE GROUP (AS OF MARCH 31, 2015)							
DISEASE SEVERITY	PROPHYLAXIS	AGE							TOTAL
		0-2 years	3-12 years	13-18 years	19-29 years	30-49 years	50-74 years	75+ years	US
Mild	Prescribed		26	25	29	11	12	0	105
			4.9%	6.4%	6.4%	2.6%	2.8%	0.0%	4.5%
	Not Prescribed/Unk	67	504	369	425	405	419	55	2244
		97.1%	95.1%	93.7%	93.6%	97.4%	97.2%	100.0%	95.5%
	Total Mild	69	530	394	454	416	431	55	2349
		100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%
Moderate	Prescribed	10	133	96	89	47	20		396
		17.9%	34.6%	39.2%	27.6%	18.3%	10.4%		26.9%
	Not Prescribed/Unk	46	252	149	233	210	173	13	1076
		82.1%	65.5%	60.8%	72.4%	81.7%	89.6%	92.9%	73.1%
	Total Moderate	56	385	245	322	257	193	14	1472
		100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%
Severe	Prescribed	65	948	589	780	455	122		2962
		34.8%	71.3%	79.1%	66.3%	48.2%	35.8%		62.6%
	Not Prescribed/Unk	122	381	156	397	489	219	8	1772
		65.2%	28.7%	20.9%	33.7%	51.8%	64.2%	72.7%	37.4%
	Total Severe	187	1329	745	1177	944	341	11	4734
		100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%
Unknown	Prescribed	0	5	4	3	3	4	0	19
		0.0%	13.2%	16.0%	8.6%	5.1%	10.0%	0.0%	9.0%
	Not Prescribed/Unk	8	33	21	32	56	36	6	192
		100.0%	86.8%	84.0%	91.4%	94.9%	90.0%	100.0%	91.0%
	Total Unknown	8	38	25	35	59	40	6	211
		100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%
All Severities	Total All	320	2282	1409	1988	1676	1005	86	8766
		100%	100%	100%	100%	100%	100%	100%	100%

Factor VIII Deficiency — Payer Profile

FACTOR VIII DEFICIENCY		PAYER PROFILE BY REGION AND TOTAL U.S. (AS OF MARCH 31, 2015)								
PAYER CATEGORY		REGION							TOTAL	
	New England	Mid-Atlantic	Southeast	Great Lakes	Northern States	Great Plains	Mountain States	Western States	US	
Medicaid	200	132	407	297	126	283	185	211	1841	
	29.1%	31.0%	40.3%	32.7%	26.8%	37.2%	30.8%	22.0%	31.6%	
Medicare	38	54	76	78	49	43	36	58	432	
	5.5%	12.7%	7.5%	8.6%	10.4%	5.7%	6.0%	6.1%	7.4%	
Private	427	233	482	399	281	376	361	323	2882	
	62.1%	54.7%	47.7%	43.9%	59.8%	49.4%	60.1%	33.7%	49.5%	
Uninsured			9		7	28	0	19	69	
			0.9%		1.5%	3.7%	0.0%	2.0%	1.2%	
Other	20		37	134	7	31	19	347	600	
	2.9%		3.7%	14.7%	1.5%	4.1%	3.2%	36.2%	10.3%	
TOTAL	688	426	1011	909	470	761	601	958	5824	
	100%	100%	100%	100%	100%	100%	100%	100%	100%	
Unknown	475	471	492	434	165	297	380	228	2942	
	40.8%	52.5%	32.7%	32.3%	26.0%	28.1%	38.7%	19.2%	33.6%	
TOTAL	1163	897	1503	1343	635	1058	981	1186	8766	
	100%	100%	100%	100%	100%	100%	100%	100%	100%	

Factor IX Deficiency

Factor IX Deficiency — Bleeding Disorder Disease Severity

FACTOR IX DEFICIENCY		DISEASE DISORDER SEVERITY BY REGION AND TOTAL U.S. (AS OF MARCH 31, 2015)							
DISEASE SEVERITY		REGION							TOTAL
	New England	Mid-Atlantic	Southeast	Great Lakes	Northern States	Great Plains	Mountain States	Western States	US
Mild	75	67	119	192	44	83	70	62	712
	28.2%	28.3%	31.7%	27.8%	22.0%	28.5%	30.0%	25.8%	28.1%
Moderate	79	82	120	364	77	131	89	51	993
	29.7%	34.6%	31.9%	52.7%	38.5%	45.0%	38.2%	21.3%	39.2%
Severe	112	88	137	135	79	77	74	127	829
	42.1%	37.1%	36.4%	19.5%	39.5%	26.5%	31.8%	52.9%	32.7%
TOTAL	266	237	376	691	200	291	233	240	2534
	100%	100%	100%	100%	100%	100%	100%	100%	100%
Unknown Severity	8	14	6	27	4	6	3	6	74
	2.9%	5.6%	1.6%	3.8%	2.0%	2.0%	1.3%	2.4%	2.8%
TOTAL	274	251	382	718	204	297	236	246	2608
	100%	100%	100%	100%	100%	100%	100%	100%	100%

Factor IX Deficiency — HIV and Hepatitis C

FACTOR IX DEFICIENCY		HIV AND HEPATITIS C (HCV) BY AGE GROUP (AS OF MARCH 31, 2015)						
AGE								TOTAL
HIV CO-MORBIDITY								
	0-2 years	3-12 years	13-18 years	19-29 years	30-49 years	50-74 years	75+ years	US
HIV	0	0	0		49	33	0	84
	0.0%	0.0%	0.0%		9.3%	8.3%	0.0%	3.2%
No HIV	79	657	382	531	477	363	35	2524
	100.0%	100.0%	100.0%	99.6%	90.7%	91.7%	100.0%	96.8%
TOTAL	79	657	382	533	526	396	35	2608
	100%	100%	100%	100%	100%	100%	100%	100%
HEPATITIS C CO-MORBIDITY								
Hepatitis C	0		0	35	224	186	7	453
	0.0%		0.0%	6.6%	42.6%	47.0%	20.0%	17.4%
No Hepatitis C	79	656	382	498	302	210	28	2155
	100.0%	99.9%	100.0%	93.4%	57.4%	53.0%	80.0%	82.6%
TOTAL	79	657	382	533	526	396	35	2608
	100%	100%	100%	100%	100%	100%	100%	100%

Factor IX Deficiency – Continuous Prophylaxis (Prescribed)

FACTOR IX DEFICIENCY		PROPHYLAXIS PRESCRIBED FOR PATIENTS BY BLEEDING DISORDER DISEASE SEVERITY AND AGE GROUP (AS OF MARCH 31, 2015)							
DISEASE SEVERITY	PROPHYLAXIS	AGE							TOTAL
		0-2 years	3-12 years	13-18 years	19-29 years	30-49 years	50-74 years	75+ years	US
Mild	Prescribed		7	7					29
			3.9%	6.4%					4.1%
	Not Prescribed/Unk	7	172	102	140	122	129	11	683
		77.8%	96.1%	93.6%	96.6%	96.8%	97.7%	91.7%	95.9%
	Total Mild	9	179	109	145	126	132	12	712
		100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%
Moderate	Prescribed	6	33	27	31	19	8	0	124
		15.4%	13.0%	17.7%	16.9%	9.7%	5.2%	0.0%	12.5%
	Not Prescribed/Unk	33	221	126	153	176	145	15	869
		84.6%	87.0%	82.4%	83.2%	90.3%	94.8%	100.0%	87.5%
	Total Moderate	39	254	153	184	195	153	15	993
		100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%
Severe	Prescribed	7	149	76	110	75	39		457
		25.9%	69.3%	69.7%	56.4%	41.0%	41.5%		55.1%
	Not Prescribed/Unk	20	66	33	85	108	55		372
		74.1%	30.7%	30.3%	43.6%	59.0%	58.5%		44.9%
	Total Severe	27	215	109	195	183	94	6	829
		100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%
Unknown	Prescribed	0	0	2	0	0	1	0	3
		0.0%	0.0%	18.2%	0.0%	0.0%	5.9%	0.0%	4.1%
	Not Prescribed/Unk	4	9	9	9	22	16	2	71
		100.0%	100.0%	81.8%	100.0%	100.0%	94.1%	100.0%	95.9%
	Total Unknown	4	9	11	9	22	17	2	74
		100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%
All Severities	Total All	79	657	382	533	526	396	35	2608
		100%	100%	100%	100%	100%	100%	100%	100%

Factor IX Deficiency — Payer Profile

FACTOR IX DEFICIENCY		PAYER PROFILE BY REGION AND TOTAL U.S. (AS OF MARCH 31, 2015)								
PAYER CATEGORY		REGION							TOTAL	
	New England	Mid-Atlantic	Southeast	Great Lakes	Northern States	Great Plains	Mountain States	Western States	US	
Medicaid	48	25	67	100	33	58	26	33	390	
	30.0%	26.3%	30.3%	30.0%	21.4%	31.0%	18.6%	17.3%	26.3%	
Medicare	19	11	25	29	15	15	12	20	146	
	11.9%	11.6%	11.3%	8.7%	9.7%	8.0%	8.6%	10.5%	9.9%	
Private	88	54	117	143	99	109	98	71	779	
	55.0%	56.8%	52.9%	42.9%	64.3%	58.3%	70.0%	37.2%	52.6%	
Uninsured				6	0				21	
				1.8%	0.0%				1.4%	
Other			10	55	7			62	145	
			4.5%	16.5%	4.6%			32.5%	9.8%	
TOTAL	160	95	221	333	154	187	140	191	1481	
	100%	100%	100%	100%	100%	100%	100%	100%	100%	
Unknown	114	156	161	385	50	110	96	55	1127	
	41.6%	62.2%	42.2%	53.6%	24.5%	37.0%	40.7%	22.4%	43.2%	
TOTAL	274	251	382	718	204	297	236	246	2608	
	100%	100%	100%	100%	100%	100%	100%	100%	100%	

Von Willebrand Disease

Von Willebrand Disease — Demographic Profile

VON WILLEBRAND DISEASE		AGE AND SEX BY REGION AND TOTAL U.S. (AS OF MARCH 31, 2015)								
		REGION							TOTAL	
		New England	Mid-Atlantic	Southeast	Great Lakes	Northern States	Great Plains	Mountain States	Western States	US
BY SEX										
Female	702	290	505	1284	270	311	205	426	3993	
	64.2%	59.1%	62.0%	65.3%	60.7%	58.5%	65.9%	59.6%	62.7%	
Male	391	201	310	681	175	221	106	289	2374	
	35.8%	40.9%	38.0%	34.7%	39.3%	41.5%	34.1%	40.4%	37.3%	
Total	1093	491	815	1965	445	532	311	715	6367	
	100%	100%	100%	100%	100%	100%	100%	100%	100%	
BY AGE										
0-2 years	12		11	17		11			70	
	1.1%		1.4%	0.9%		2.1%			1.1%	
3-12 years	333	122	215	472	123	173	74	238	1750	
	30.5%	24.9%	26.4%	24.0%	27.6%	32.5%	23.8%	33.3%	27.5%	
13-18 years	335	110	213	471	76	169	74	229	1677	
	30.7%	22.4%	26.1%	24.0%	17.1%	31.8%	23.8%	32.0%	26.3%	
19-29 years	240	112	167	426	97	88	53	149	1332	
	22.0%	22.8%	20.5%	21.7%	21.8%	16.5%	17.0%	20.8%	20.9%	
30-49 years	90	75	125	317	88	46	51	57	849	
	8.2%	15.3%	15.3%	16.1%	19.8%	8.7%	16.4%	8.0%	13.3%	
50-74 years	78	60	73	235	47	43	51	34	621	
	7.1%	12.2%	9.0%	12.0%	10.6%	8.1%	16.4%	4.8%	9.8%	
75+ years		7	11	27	9				68	
		1.4%	1.4%	1.4%	2.0%				1.1%	
Total	1093	491	815	1965	445	532	311	715	6367	
	100%	100%	100%	100%	100%	100%	100%	100%	100%	

Age (years)	Mean	Standard Deviation	Median
	24	17	18

Von Willebrand Disease — Disease Types

VON WILLEBRAND DISEASE	VWD TYPES AND SUBTYPES — TOTAL U.S. (AS OF MARCH 31, 2015)		
VWD TYPE	TOTAL U.S.	SUBTYPE	% OF TYPE
VWD, Type 1	5122		
	83.0%		
		Type 1	5099
			99.6%
		Type 1C	23
			0.4%
VWD, Type 2	825		
	13.4%		
		Type 2	132
			16.0%
		Type 2A	307
			37.2%
		Type 2B	204
			24.7%
		Type 2M	133
			16.1%
		Type 2N	49
			5.9%
VWD, Type 3	225		
	3.6%		
		Type 3	225
			100.0%
TOTAL w Type Specified	6172		
	100%		
VWD, Type Other/Unknown	195		
	3.1%		
TOTAL	6367		
	100%		

Von Willebrand Disease — HIV and Hepatitis C

VON WILLEBRAND DISEASE		HIV AND HEPATITIS C (HCV) BY AGE GROUP (MARCH 31, 2015)						
AGE								TOTAL
HIV CO-MORBIDITY								
	0-2 years	3-12 years	13-18 years	19-29 years	30-49 years	50-74 years	75+ years	US
HIV	0	0	0		6		0	10
	0.0%	0.0%	0.0%		0.7%		0.0%	0.2%
No HIV	70	1750	1677	1331	843	618	68	6357
	100.0%	100.0%	100.0%	99.9%	99.3%	99.5%	100.0%	99.8%
TOTAL	70	1750	1677	1332	849	621	68	6367
	100%	100%	100%	100%	100%	100%	100%	100%
HEPATITIS C CO-MORBIDITY								
Hepatitis C	0	0	0	6	38	64	6	114
	0.0%	0.0%	0.0%	0.5%	4.5%	10.3%	8.8%	1.8%
No Hepatitis C	70	1750	1677	1326	811	557	62	6253
	100.0%	100.0%	100.0%	99.6%	95.5%	89.7%	91.2%	98.2%
TOTAL	70	1750	1677	1332	849	621	68	6367
	100%	100%	100%	100%	100%	100%	100%	100%

Definitions

Definitions – Regions

DEFINITION OF REGIONS	
New England Region	Regions I and II
Mid-Atlantic Region	Region III
Southeast Region	Region IV-N and IV-S
Great Lakes Region	Region V-E
Northern States Region	Region V-W
Great Plains Region	Region VI and VII
Mountain States Region	Regions VIII and X
Western States Region	Region IX
Region I	State equals: MA, CT, ME, VT, NH, RI
Region II	State equals: NY, NJ, PR
Region III	State equals: PA, DC, VA, DE, WV, MD
Region IV-N	State equals: NC, SC, KY, TN
Region IV-S	State equals: GA, FL, AL, MS
Region V-E	State equals: MI, OH, IN
Region V-W	State equals: WI, IL, MN, ND, SD
Region VI	State equals: TX, LA, AR, OK
Region VII	State equals: MO, IA, NE, KS
Region VIII	State equals: CO, NM, AZ, UT, MT, WY
Region IX	State equals: CA, HI, GU, NV
Region X	State equals: OR, WA, AK, ID

Definitions – Clinical Content

DEFINITION OF CLINICAL CONTENT	
Factor VIII Deficiency	Hemophilia A
Factor IX Deficiency	Hemophilia B, also known as Christmas disease
Factor VIII/IX Disease Severity	
Factor VIII/IX Deficiency (Mild)	Condition resulting from a level of clotting activity of >5% of normal activity in the bloodstream (Normal range of factor VIII or IX is 50-200%)
Factor VIII/IX Deficiency (Moderate)	Condition resulting from a level of clotting activity of 1-5% of normal activity in the bloodstream (Normal range of factor VIII or IX is 50-200%)
Factor VIII/IX Deficiency (Severe)	Condition resulting from a level of clotting activity of <1% of normal activity in the bloodstream (Normal range of factor VIII or IX is 50-200%)
Von Willebrand Disease (VWD)	
VWD, Type 1	Includes subtype 1C
VWD, Type 2	Includes subtypes 2, 2A, 2B, 2M, 2N, type 2 unknown subtype
VWD, Type 3	No subtypes
VWD, Type Other/Unknown	Includes acquired VWD
Rare Disorders	Includes disorders resulting from deficiency of Factor I (fibrinogen), Factor II, Factor V (not Factor V Leiden), Factor V and VIII, Factor X, Factor XI, Factor XII, Factor XIII, PAI-1, Protein S, Protein C as well as Ehlers-Danlos syndrome and Hereditary Hemorrhagic Telangiectasia (Osler-Weber-Rendu)
Platelet Disorders	Includes Bernard Soulier; Glanzmann Thrombasthenia; Grey Platelet Syndrome; Hermansky-Pudlak Syndrome; Platelet Function Disorder, Hereditary; Platelet Function Disorder, Acquired; Release Defect; as well as Storage Pool Deficiency

Definitions – Medications

DEFINITION OF MEDICATIONS	
F-VIII Replacement: Recombinant Factor VIII Concentrates	Advate (Baxter), Helixate FS (CSL), Kogenate FS (Bayer), NovoEight (NovoNordisk), Recombinate (Baxter), ReFacto AF (Pfizer), Xyntha (Pfizer), Eloctate (Biogen)
F-VIII Replacement: Human Plasma Derived Factor VIII Concentrates (*rich in Von Willebrand factor)	Alphanate (Grifols)*, Humate-P (CSL)*, Koate DVI (Kedrion)*, Hemophil (Baxter), Monoclate-P (CSL), Monarc-M (Baxter)
F-IX Replacement: Recombinant Factor IX Concentrates	BeneFIX (Pfizer) - non-VWD factor containing products, Alprolix (Biogen), Rixubis (Baxter)
F-IX Replacement: Human Plasma Derived Factor IX Concentrates	AlphaNine SD (Grifols), MonoNine (CSL)
VWD Treatments: VWF-Containing Factor VIII Concentrates (Human Plasma Derived)	Alphanate (Grifols), Humate-P (CSL), Wilate (Octapharma)
F-XIII Replacement	Corifact (CSL), Tretten (NovoNordisk)
Bypassing Agents	NovoSeven RT (Novo Nordisk), FEIBA (Baxter), Autoplex T
Immune Tolerance Induction (ITI)	Immune modulating drugs may include, but are not limited, to the following: corticosteroids, cyclophosphamide (Cytoxan®), mycophenolate mofetil (CellCept®), mycophenolic acid (Myfortic®), azathioprine (Imuran®, Azasan®), tacrolimus (Prograf®, Hecoria®), sirolimus (Rapamune®), cyclosporine (Sandimmune®), IVIg (Carimune®, Flebogamma®, Gammagard®, Gammalex®, Hizentra®, Privigen®, Vivaglobin®), and rituximab (Rituxan®).
Blood Bank Products	Cryoprecipitate, Fresh-frozen plasma, Platelets, Packed RBCs or whole blood
Hepatitis C treatment regimens	Interferon, PEG-interferon, EPO, ribavirin, boceprevir, telaprevir
Desmopressin Formulations	DDAVP injection, Stimate spray

Definitions — Patient Sample

DEFINITION OF PATIENT SAMPLE	
ATHNdataset Population	The population includes only those individuals who receive care at one of the participating HTCs. Individuals actively "opt in" to the ATHNdataset. Each participant has signed a patient authorization form indicating willingness to share data as part of the ATHNdataset.
Small Cell Size	Cell with 5 or fewer cases

Definitions — Participating HTC's by Region

LIST OF PARTICIPATING HTC'S BY REGION			
Region	ATHN Affiliate	City	State
I	Boston Hemophilia Center at Boston Children's Hospital	Boston	MA
I	Boston Hemophilia Center- Brigham and Women's Hospital	Boston	MA
I	Dartmouth-Hitchcock Comprehensive Hemophilia and Thrombosis Center	Lebanon	NH
I	Maine Hemophilia and Thrombosis Center	Scarborough	ME
I	Massachusetts General Hospital for Children	Boston	MA
I	New England Hemophilia Center/UMass Memorial Hospital	Worcester	MA
I	Rhode Island Hospital Hemostasis and Thrombosis Center	Providence	RI
I	University of Connecticut Health Center & Connecticut Children's Medical Center	Hartford	CT
I	Vermont Regional Hemophilia Center	Burlington	VT
I	Yale Hemophilia Center	New Haven	CT
II	Albany Regional Hemophilia & von Willebrand Treatment Center	Albany	NY
II	Hemophilia Center of Western New York, Inc.	Buffalo	NY
II	Long Island Jewish Medical Center Comprehensive Hemophilia Center	New Hyde Park	NY
II	Mary M. Gooley Hemophilia Center, Inc.	Rochester	NY
II	Mount Sinai Regional Comprehensive Hemophilia Treatment Center	New York	NY
II	Nadeene Brunini Comprehensive Hemophilia Care Center / St. Michael's Medical Center	Newark	NJ
II	Newark Beth Israel Medical Center - Hemophilia Center	Newark	NJ
II	Puerto Rico Hemophilia Treatment Center	San Juan	PR
II	SUNY Upstate Medical University-Adult Program	Syracuse	NY
II	SUNY Upstate Medical University-Pediatric Program	Syracuse	NY
II	UMDNJ-Robert Wood Johnson University Hospital	New Brunswick	NJ
II	Weill Cornell Medical College - New York Presbyterian Hospital	New York	NY

Definitions — Participating HTC by Region

LIST OF PARTICIPATING HTCS BY REGION			
Region	ATHN Affiliate	City	State
III	Central Virginia Center for Coagulation Disorders / Virginia Commonwealth University	Richmond	VA
III	Charleston Area Medical Center	Charleston	WV
III	Children's Hospital of Philadelphia (CHOP)	Philadelphia	PA
III	Children's Hospital of the King's Daughters	Norfolk	VA
III	Children's National Hemophilia Center	Washington	DC
III	Georgetown University	Washington	DC
III	Hemophilia Center of Central Pennsylvania / Penn State Milton S. Hershey Medical Center	Hershey	PA
III	Hemophilia Center of Western Pennsylvania	Pittsburgh	PA
III	Johns Hopkins University Hemophilia Treatment Center	Baltimore	MD
III	Lehigh Valley Hospital	Bethlehem	PA
III	Pediatric Hematology Program University of Virginia	Charlottesville	VA
III	Penn Comprehensive Hemophilia and Thrombophilia Program/Hospital of the University of Pennsylvania	Philadelphia	PA
III	West Virginia University Medical Center Hemophilia Treatment Center	Morgantown	WV
IV - North	Brody School of Medicine at East Carolina University	Greenville	NC
IV - North	Comprehensive Hemophilia Treatment Center, University of North Carolina at Chapel Hill	Chapel Hill	NC
IV - North	Duke University Health System	Durham	NC
IV - North	East Tennessee Comprehensive Hemophilia Center	Knoxville	TN
IV - North	Palmetto Health Richland	Columbia	SC
IV - North	St. Jude Children's Research Hospital	Memphis	TN
IV - North	University of Kentucky Hemophilia Treatment Center	Lexington	KY
IV - North	University of Louisville Hemophilia Treatment Center	Louisville	KY
IV - North	University of Tennessee - Memphis	Memphis	TN

Definitions — Participating HTC by Region

LIST OF PARTICIPATING HTCS BY REGION			
Region	ATHN Affiliate	City	State
IV - North	Vanderbilt University Medical Center	Nashville	TN
IV - North	Wake Forest University Health Sciences	Winston-Salem	NC
IV - South	All Children's Hospital	St. Petersburg	FL
IV - South	Children's Hospital @ Memorial University Medical Center	Savannah	GA
IV - South	Comprehensive Bleeding Disorders Center at Emory University and Children's Health Care of Atlanta	Atlanta	GA
IV - South	Georgia Regents University - Adult Hemophilia Treatment Center	Augusta	GA
IV - South	Georgia Regents University Pediatric Hemophilia Treatment Center	Augusta	GA
IV - South	Nemours Children's Clinic of Jacksonville / The Nemours Foundation	Jacksonville	FL
IV - South	Pediatric Hematology/Oncology of St. Joseph's Children's Hospital - Tampa	Tampa	FL
IV - South	University of Alabama Birmingham	Birmingham	AL
IV - South	University of Miami Comprehensive Hemophilia Treatment Center	Miami	FL
IV - South	University of Mississippi Medical Center	Jackson	MS
IV - South	University of South Florida Adult Comprehensive Hemophilia Treatment Center	Tampa	FL
V - East	Akron Children's Hospital HTC	Akron	OH
V - East	Children's Hospital of Michigan Hemostasis and Thrombosis Center	Detroit	MI
V - East	Cincinnati Children's Hospital Medical Center, Hemophilia & Thrombosis Center	Cincinnati	OH
V - East	DeVos Children's Coagulation Disorders Program	Grand Rapids	MI
V - East	Eastern Michigan Hemophilia Treatment Center Hurley Medical Center	Flint	MI
V - East	Hemophilia Clinic - West Michigan Cancer Center	Kalamazoo	MI
V - East	Henry Ford Health System Bleeding and Thrombosis Treatment Center	Detroit	MI
V - East	Indiana Hemophilia and Thrombosis Center	Indianapolis	IN
V - East	Karmanos Cancer Center/Detroit Receiving Hospital and University Medical Center	Detroit	MI

Definitions — Participating HTC's by Region

LIST OF PARTICIPATING HTC'S BY REGION			
Region	ATHN Affiliate	City	State
V - East	Michigan State University Center for Bleeding Disorders & Clotting	East Lansing	MI
V - East	Nationwide Children's Hospital Columbus	Columbus	OH
V - East	Northern Regional Bleeding Disorder Center at Munson Medical Center	Traverse City	MI
V - East	Northwest Ohio Hemophilia Treatment Center at the Toledo Hospital	Toledo	OH
V - East	Ohio State University Medical Center Hemophilia Treatment Center	Columbus	OH
V - East	University Hospitals Health System Cleveland	Cleveland	OH
V - East	University of Cincinnati Medical Center Hemophilia Treatment Center	Cincinnati	OH
V - East	University of Michigan Hemophilia and Coagulation Disorders	Ann Arbor	MI
V - East	West Central Ohio Hemophilia Center - Dayton Children's Hospital	Dayton	OH
V - East	West Michigan Pediatric at Bronson	Kalamazoo	MI
V - West	Ann & Robert H. Lurie Children's Hospital of Chicago	Chicago	IL
V - West	Bleeding and Clotting Disorders Institute	Peoria	IL
V - West	Children's Hospitals & Clinics of Minnesota	Minneapolis	MN
V - West	Comprehensive Center for Bleeding Disorders, Milwaukee	Wauwatosa	WI
V - West	Gundersen Lutheran Administrative Services, Inc.	LaCrosse	WI
V - West	Hemophilia Outreach Center Green Bay	Green Bay	WI
V - West	North Dakota Hemophilia & Thrombophilia Treatment Center	Fargo	ND
V - West	Northwestern Center for Bleeding Disorders	Chicago	IL
V - West	Rush University Medical Center	Chicago	IL
V - West	South Dakota Center for Blood Disorders	Sioux Falls	SD
V - West	Stroger Hospital of Cook County - Adults	Chicago	IL
V - West	Stroger Hospital of Cook County - Pediatrics	Chicago	IL

Definitions — Participating HTC by Region

LIST OF PARTICIPATING HTCS BY REGION			
Region	ATHN Affiliate	City	State
V - West	University of Minnesota Medical Center, Fairview	Minneapolis	MN
V - West	UWHC Comprehensive Program for Bleeding Disorders	Madison	WI
Great Plains	Arkansas Center for Bleeding Disorders	Little Rock	AR
Great Plains	Children's Mercy Hospital - Kansas City	Kansas City	MO
Great Plains	Childrens Hosptial New Orleans	New Orleans	LA
Great Plains	Fort Worth Bleeding Disorders Program	Fort Worth	TX
Great Plains	Gulf States Hemophilia and Thrombophilia Center	Houston	TX
Great Plains	Hemophilia Treatment Center - Adult Program Saint Louis University	St. Louis	MO
Great Plains	Iowa Hemophilia and Thrombosis Center	Iowa City	IA
Great Plains	Louisiana Center for Bleeding and Clotting Disorders, Tulane University Health Science Center	New Orleans	LA
Great Plains	Nebraska Regional Hemophilia Treatment Center	Omaha	NE
Great Plains	North Texas Comprehensive Hemophilia Treatment Center	Dallas	TX
Great Plains	North Texas Hemophilia and Thrombosis Program - Pediatric Program / Center for Cancer & Blood Disorder	Dallas	TX
Great Plains	Oklahoma Center for Bleeding & Clotting Disorders	Oklahoma City	OK
Great Plains	Texas Children's Hemophilia & Thrombosis Center/Baylor College of Medicine	Houston	TX
Great Plains	The John Bouhasin Center for Children with Bleeding Disorders	Saint Louis	MO
Great Plains	Washington University Center in St. Louis - Adult Program	St Louis	MO
Great Plains	Washington University Center in St. Louis - Pediatric Program	St Louis	MO
VIII	Arizona Hemophilia and Thrombosis Center / University of Arizona Health Science Center	Tucson	AZ
VIII	Arizona Hemophilia and Thrombosis Treatment Center at Phoenix Children's Hospital	Phoenix	AZ
VIII	Intermountain Hemophilia and Thrombosis Center	Salt Lake City	UT
VIII	University of Colorado Denver Hemophilia and Thrombosis Center	Aurora	CO

Definitions — Participating HTC by Region

LIST OF PARTICIPATING HTCS BY REGION			
Region	ATHN Affiliate	City	State
VIII	University of New Mexico Ted R. Montoya Hemophilia & Thrombosis Program	Albuquerque	NM
IX	Center for Comprehensive Care and Diagnosis of Inherited Blood Disorders	Orange	CA
IX	Childrens Hospital Los Angeles	Los Angeles	CA
IX	Children's Hospital of Central California	Madera	CA
IX	Children's Hospital Research Center Oakland	Oakland	CA
IX	City of Hope Medical Center	Duarte	CA
IX	Guam Comprehensive Hemophilia Care Program	Guam	GU
IX	Hemophilia Treatment Center of Nevada	Las Vegas	NV
IX	Kapiolani Medical Center for Women and Children	Honolulu	HI
IX	LPCH/Stanford University HTC	Palo Alto	CA
IX	Orthopaedic Hospital of Los Angeles	Los Angeles	CA
IX	Rady Children's Hospital San Diego	San Diego	CA
IX	University of California at Davis Hemophilia Treatment Center	Sacramento	CA
IX	University of California, San Diego Hemophilia & Thrombosis Treatment Center	San Diego	CA
IX	University of California, San Francisco Hemophilia & Thrombosis Center	San Francisco	CA
X	Alaska Hemophilia Treatment Center	Anchorage	AK
X	Providence Sacred Heart Medical Center and Children's Hospital	Spokane	WA
X	Puget Sound Blood Center	Seattle	WA
X	Seattle Children's Hospital and Regional Medical Center	Seattle	WA
X	St. Luke's Hemophilia Center	Boise	ID
X	The Hemophilia Center at Oregon Health & Science University	Portland	OR



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ATHN is a 501(c)(3) tax exempt organization.

our vision. *To advance and improve the care of individuals affected by bleeding and thrombotic disorders.*

our mission. *To provide stewardship of a secure national database, adherent to all privacy guidelines, which will be used to support clinical outcomes analysis, research, advocacy and public health reporting in the hemostasis and thrombosis community.*

our values. *Improving clinical outcomes and care, facilitating continuity of care, fostering collaboration, maintaining confidentiality, conserving resources through a common infrastructure.*