

# A Summary of Hansen's Disease in the United States-2014

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U.S. Department of Health and Human Services  
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National Hansen's Disease Program



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## **Introduction**

The mission of the Health Resources and Services Administration (HRSA), Healthcare Systems Bureau's Division of National Hansen's Disease Programs (NHDP) is to conduct research, educate patients and health care providers, and provide direct medical services to Hansen's Disease (HD [a.k.a. leprosy]) patients in the United States (U.S.) and its territories. In carrying out this mission, the program collects beneficiary information and maintains a National Hansen's Disease Registry (Registry). The Registry is a computerized database that provides operational information for administrative reports and an epidemiological resource for certain clinical, rehabilitative and laboratory-based research.

Registry data are collected through the cooperative assistance of health care providers and a network of state and local health care agencies. Patient information is provided through delivery of the HD Surveillance Form, which serves as the instrument for processing new cases into the Registry. When the NHDP becomes aware of a new HD case, an HD surveillance form is sent to the provider to obtain the data needed to register the patient. Additionally, this form can be downloaded from the NHDP website at <http://www.hrsa.gov/hansens/>. Registry data also are reported by various state and local government agencies through the same surveillance form.

HD is monitored by several agencies, and data reported to the Registry is shared with the Centers for Disease Control and Prevention (CDC) and the World Health Organization (WHO) without personally identifiable information. In addition, summary reports or customized studies addressing special data inquiries are provided to other governmental agencies and qualified academic researchers as needed. The Registry is a record of basic demographic information on U.S. HD cases presenting since 1894. The majority of all U.S. cases registered have presented since 1983 (median year). The total number of U.S. cases registered by the end of 2014 was 13,765. The following is a general demographic summary of the cases reported in 2014 and the last decade.

## **Incidence and Prevalence of HD in the U.S.**

The NHDP derives operational values similar to epidemiological expressions of incidence and prevalence of HD in the U.S. from the Registry data. The number of cases newly reported to the Registry within a given calendar year is considered to be our operational equivalent of annual incidence. Similarly, an operational expression of prevalence is derived from the total number of cases in the Registry. Since care for HD and related medical problems is an entitlement that is unaffected by an individual's drug therapy or treatment status, we use an operational definition of HD prevalence that reflects the total number of individuals potentially eligible for our services, and we estimate that number according to the likely life expectancy of all individuals recorded in the Registry.

A total of 175 cases were newly reported to the Registry in 2014. This number includes the addition of 10 cases that presented in previous years but had gone unregistered. These additions are in keeping with the general trend in new case reporting seen over the last decade (Figure 1). Temporal variation in presentation is not uncommon with chronic diseases and can be influenced by a variety of factors. Declines in annual case registrations were seen coincident to relocation of the Program from Carville, Louisiana, to its current Baton Rouge campus in the late 1990's. Annual case registrations have generally increased since that time and may have been enhanced by NHDP efforts to increase awareness of HD through several national seminars and scientific programs.

With this number of newly recorded cases, a total of 13,765 HD cases have been registered in the U.S. since 1894. Based on estimates of life expectancy, some 8,081 of these cases are potentially still living and may be eligible for services from the NHDP for HD or HD-related medical care. Other program segments detail the exact numbers of cases which utilize services each year and that summary of activity is not repeated here.

## **Geographic Distribution**

HD cases were reported from 32 U.S. States and Puerto Rico in 2014 (Table 1a). A 10-year summary of reported cases is shown in Table 1b, and a graphical representation with comparison to the 10-year trend is shown in Figures 2 and 3, respectively. Florida, California, New York, Louisiana, Texas, and Hawaii contributed the largest number of cases in 2014, and collectively accounted for 63 percent (119/175) of the cases registered. The predominance of states is in keeping with the 10-year trend with more than 60% of reported cases arising in those same locations over the last decade.

Autochthonous foci of HD transmission are recognized in Hawaii, Puerto Rico, and on the U.S. mainland in the region of the western Gulf of Mexico. Some speculate that it also may occur in California. In 2014, a total of 14 cases were reported from Hawaii and 3 from Puerto Rico. Reporting from Hawaii is in keeping with the historical trend; 13/14 of the Hawaiian cases occurred among individuals who had come to Hawaii from U.S. Territories or U.S.-affiliated Pacific islands (USAPI).

A total of 79 cases were reported from Texas (16), Louisiana (16), Arkansas (9), Mississippi (4), and Florida (34), areas where *M. leprae* has been recovered from wild armadillos. The combined number of cases is consistent with the historical norms from these states, although Florida shows an increasing trend. More than two-thirds (56/79) of all these cases were native-born U.S. citizens with no residence history outside the U.S. This indicates ongoing indigenous transmission within the population. HD has occurred in this region since the 1700s and recent evidence suggests that zoonotic transmission from nine-banded armadillos is the principle source of infection perpetuating the infection in these locales.

## **National Origin**

Of the 175 reported cases, 109 (62 percent) recorded a location other than the U. S. as their place of birth. Collectively, national origin of the cases reported in 2010 could be associated with a total of 24 different countries or territories (Table 2). Of the 24 different birth countries reported, the largest numbers were born in the U.S. (66) or U.S. territories (29). These data highlight a recent trend for high rates of disease in the Pacific Island jurisdictions that began to emerge in the late 1960s and that have increased markedly in the last decades. These same patterns are generally reflected in the 10-year summary trend, except notably fewer cases are now being registered among persons immigrating from Cuba or Vietnam (Table 3).

The World Health Organization (WHO) and allied non-government organizations (NGO's) have sponsored global campaigns for the "Elimination of Leprosy as a Public Health Problem" for some 25 years now – the primary aim being to reduce national prevalence to less than 1:10,000 persons by providing antibiotic therapy for the disease. Through these efforts, thousands of individuals have been microbiologically cured of their disease. In 2014, WHO reported that only 213,899 new cases were registered worldwide, representing a greater than 60 percent decline in annual new case numbers since 2001. There is some evidence that the declining case numbers may be associated with incomplete reporting due to a general erosion of infrastructure for global control of HD. Regardless, nearly all of the reduction observed has been within countries in Southeast Asia, a region which contributes fewer than 10 percent of the cases encountered in the U. S. New case presentation rates in the rest of the global community appear to be relatively steady, except those within the South Pacific region where new case detection and reporting appear to be continually increasing.

## **Race or Ethnicity**

The ethnic or racial association identified by cases reporting in 2014 is shown in Figure 4 and the associated Table 4. The 2014 distribution of ethnicities was in keeping with the 10-year trend and shows a broad involvement of ethnic groups. In 2014, the largest numbers of cases (53/175, 30 percent) identify themselves as being Asian or South Pacific Islanders. The largest individual racial group continues to be Whites of non-Hispanic origin (67/175, 38 percent).

## **Disease Classification**

The HD surveillance form provides for initial classification of the disease into one of six categories which correspond to the universal ICD-9-CM diagnosis codes for HD (030.0-030.3, 030.8, and 030.9). This method of reporting disease classification is completed more consistently than the other classification methods on the HD Surveillance Form. The diagnosis code distribution of classifications registered in 2014 is shown in Table 5 and depicted graphically in Figures 5a and 5b. The majority (154/175, 88 percent) of U.S. cases is coded as either 030.0 or 030.1 and corresponds to either lepromatous (52 percent) or tuberculoid (36 percent) disease respectively. Comparing these percentages to the 10-year trend of reported codes shows no significant variation, and these 2014 diagnostic codings are in keeping with earlier observations.

Most leprosy specialists prefer the Ridley-Jopling classification system, which includes both the lepromatous and tuberculoid ends of the spectrum as well as the associated borderline-lepromatous, borderline-tuberculoid, and an indeterminate classification. This can be important in terms of prognosis and follow-up for potential untoward reactions. Unfortunately, Ridley-Jopling classification data are frequently omitted from the HD Surveillance Form. Some clinicians may not know the disease classification when they report the case and others may be unaware of this

classification system. The reported Ridley-Jopling classifications in 2014, and their 10-year trends, are shown in Table 5 section B and the accompanying figures. Consistent with the diagnosis code data nearly 40 percent (69/175) of U.S. cases are classified as lepromatous, and 27 percent (48/175) express borderline forms of the disease, while a similar number of cases are classified as tuberculoid (36/175, 20 percent).

The WHO assesses cases only as “Multibacillary” or “Paucibacillary”. A category of Multibacillary cases can be created by combining the Borderline, Borderline-lepromatous and Lepromatous classes from the ICD-9 codes. Likewise, Paucibacillary cases can be identified by grouping the remaining categories. For 2014, 101/175 (58 percent) of the reported cases are grouped as Multibacillary and 69/175 (39 percent) as Paucibacillary according to this classification scheme. These data, too, are in keeping with the 10-year trend of reporting as summarized in Table 5 section C, and illustrated graphically for 2014 in Figures 5a and for the preceding 10-year period in Figure 5b.

### **Age and Gender**

Of the 175 cases reported to the registry in 2014, 72 percent (126/175) were male and 38 percent (49/175) were female (Table 6). These data are in keeping with long-term trends in the gender distribution of U.S. cases (Table 6). While the gender ratio can differ dramatically in various areas throughout the world, the 2:1 male/female ratio generally reported for this disease closely approximates that seen over the last 10 years in the U.S. (Figure 6).

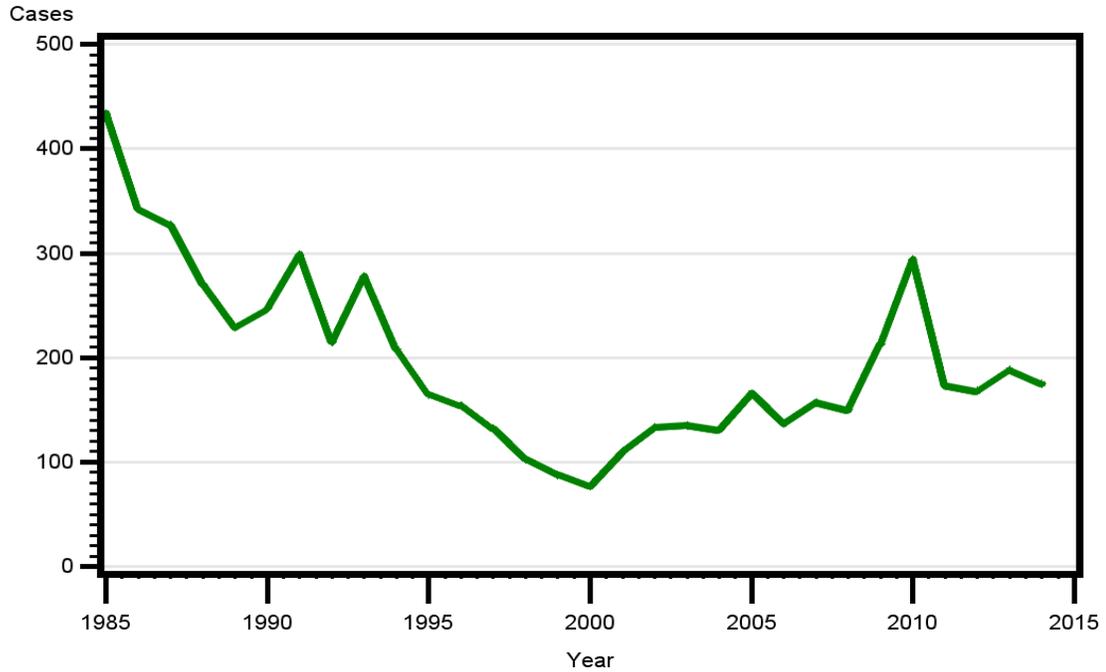
The age distribution of U.S. cases in 2014 and the preceding 10 years is summarized in Table 7 and also shown in Figure 7. Further demographic breakdown of cases by age and gender is also shown in Tables 8a and 8b. In 2014, the age of all registrants ranged from 3 to 90 years. Obviously, the age of attack varies markedly within the U.S., and all age groups are vulnerable to this disease. The majority of U.S. cases occur among middle-aged adult males. This general trend of a broad age range of attack has remained relatively consistent over the last 10 years. Therefore, support services must be considered for patients of all age categories, and no particular age group should be considered more at-risk than another.

### **Contact Information:**

Specific questions or other inquiries for data or analysis should be directed to:

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1770 Physician’s Park Drive  
Baton Rouge, Louisiana 70816  
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**Figure 1: U.S. Reported Hansen’s Disease Cases by Year 1985-2014**



<b>30 Year Data Table for Figure 1.</b>					
<b>Year</b>	<b>Number of Cases</b>	<b>Year</b>	<b>Number of Cases</b>	<b>Year</b>	<b>Number of Cases</b>
<b>1985</b>	434	<b>1995</b>	165	<b>2005</b>	166
<b>1986</b>	342	<b>1996</b>	154	<b>2006</b>	137
<b>1987</b>	327	<b>1997</b>	132	<b>2007</b>	157
<b>1988</b>	270	<b>1998</b>	103	<b>2008</b>	150
<b>1989</b>	229	<b>1999</b>	88	<b>2009</b>	213
<b>1990</b>	247	<b>2000</b>	77	<b>2010</b>	294
<b>1991</b>	299	<b>2001</b>	110	<b>2011</b>	173
<b>1992</b>	215	<b>2002</b>	133	<b>2012</b>	168
<b>1993</b>	278	<b>2003</b>	135	<b>2013</b>	188
<b>1994</b>	208	<b>2004</b>	131	<b>2014</b>	175

**Table 1a: 2014 Summary of U.S. HD Cases by Reporting Jurisdiction**

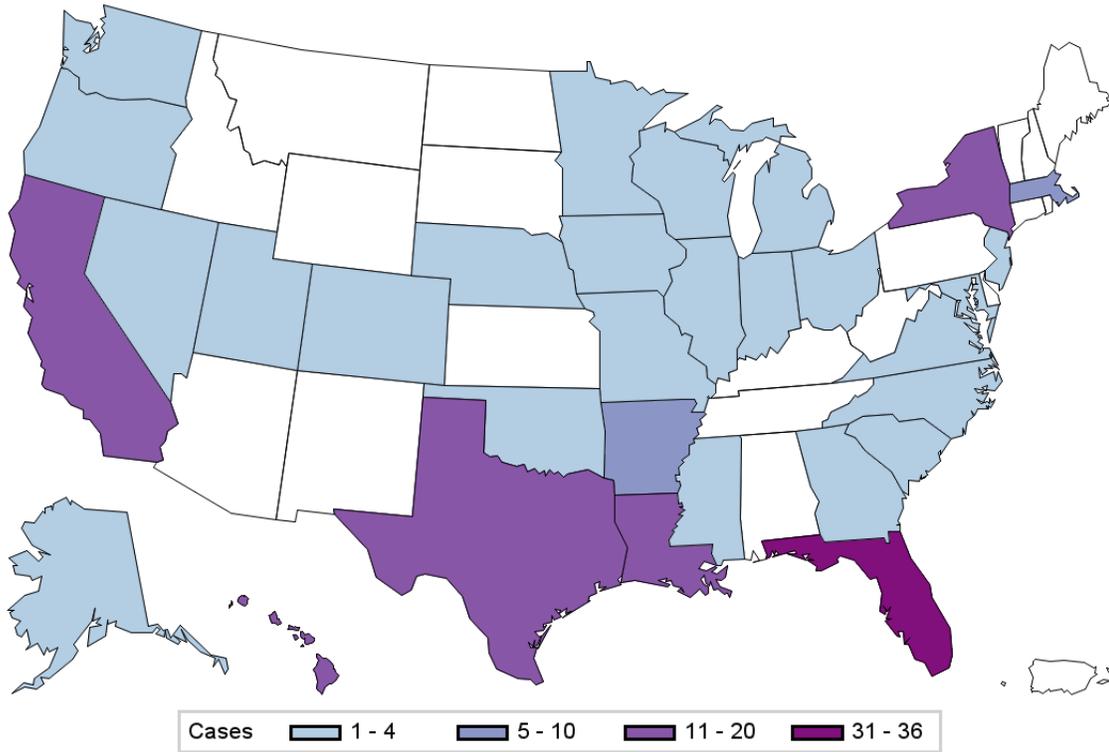
<b>2014 Reporting by Jurisdiction</b>	<b>Number of Cases</b>	<b>Percent of Total Cases</b>
ALASKA	1	0.57%
ARKANSAS	9	5.14%
CALIFORNIA	20	11.43%
COLORADO	2	1.14%
FLORIDA	34	19.43%
GEORGIA	1	0.57%
HAWAII	14	8.00%
ILLINOIS	1	0.57%
INDIANA	1	0.57%
IOWA	1	0.57%
LOUISIANA	16	9.14%
MARYLAND	2	1.14%
MASSACHUSETTS	5	2.86%
MICHIGAN	1	0.57%
MINNESOTA	2	1.14%
MISSISSIPPI	4	2.29%
MISSOURI	2	1.14%
NEBRASKA	1	0.57%
NEVADA	1	0.57%
NEW JERSEY	1	0.57%
NEW YORK	19	10.86%
NORTH CAROLINA	1	0.57%
OHIO	4	2.29%
OKLAHOMA	1	0.57%
OREGON	1	0.57%
PUERTO RICO	3	1.71%
SOUTH CAROLINA	1	0.57%
TEXAS	16	9.14%
UTAH	3	1.71%
VIRGINIA	2	1.14%
WASHINGTON	3	1.71%
WISCONSIN	2	1.14%

**Table 1b: 10-Year Summary (2004-2013) of U.S. Cases by Reporting Jurisdiction**

<b>Jurisdiction</b>	<b>Number of Cases</b>	<b>Percent of Total Cases</b>
Missing	2	0.11%
ALABAMA	6	0.34%
ALASKA	2	0.11%
ARIZONA	20	1.13%
ARKANSAS	44	2.48%
CALIFORNIA	230	12.94%
COLORADO	12	0.68%
CONNECTICUT	13	0.73%
DELAWARE	1	0.06%
DISTRICT OF COLUMBIA	3	0.17%
FLORIDA	171	9.62%
GEORGIA	32	1.80%
GUAM	1	0.06%
HAWAII	216	12.16%
IDAHO	2	0.11%
ILLINOIS	37	2.08%
INDIANA	4	0.23%
IOWA	15	0.84%
KANSAS	2	0.11%
KENTUCKY	5	0.28%
LOUISIANA	138	7.77%
MAINE	1	0.06%
MARYLAND	15	0.84%
MASSACHUSETTS	119	6.70%
MICHIGAN	8	0.45%
MINNESOTA	18	1.01%
MISSISSIPPI	18	1.01%
MISSOURI	16	0.90%
MONTANA	1	0.06%
NEBRASKA	4	0.23%
NEVADA	11	0.62%
NEW HAMPSHIRE	2	0.11%
NEW JERSEY	24	1.35%

<b>Jurisdiction</b>	<b>Number of Cases</b>	<b>Percent of Total Cases</b>
<b>NEW MEXICO</b>	5	0.28%
<b>NEW YORK</b>	144	8.10%
<b>NORTH CAROLINA</b>	11	0.62%
<b>OHIO</b>	16	0.90%
<b>OKLAHOMA</b>	11	0.62%
<b>OREGON</b>	26	1.46%
<b>PENNSYLVANIA</b>	24	1.35%
<b>PUERTO RICO</b>	48	2.70%
<b>RHODE ISLAND</b>	5	0.28%
<b>SOUTH CAROLINA</b>	6	0.34%
<b>SOUTH DAKOTA</b>	2	0.11%
<b>TENNESSEE</b>	7	0.39%
<b>TEXAS</b>	200	11.25%
<b>UTAH</b>	11	0.62%
<b>VERMONT</b>	2	0.11%
<b>VIRGINIA</b>	9	0.51%
<b>WASHINGTON</b>	47	2.64%
<b>WEST VIRGINIA</b>	2	0.11%
<b>WISCONSIN</b>	6	0.34%

**Figure 2: 2014 U.S. HD cases by Reporting Jurisdiction**





**Table 2: 2014 U.S. HD Cases by Birth Country**

<b>Country of Birth</b>	<b>Number of Cases</b>	<b>Percent of Total Cases</b>
AMERICAN SAMOA	1	0.57%
BHUTAN	2	1.14%
BRAZIL	6	3.43%
BURMA	2	1.14%
CHINA	1	0.57%
CONGO	1	0.57%
DOMINICAN REPUBLIC	5	2.86%
EGYPT	1	0.57%
ETHIOPIA	1	0.57%
FRANCE	1	0.57%
GAMBIA	1	0.57%
GUAM	1	0.57%
HAITI	2	1.14%
INDIA	18	10.29%
LAOS	1	0.57%
MEXICO	10	5.71%
MICRONESIA	14	8.00%
NEPAL	1	0.57%
PHILIPPINES	9	5.14%
PUERTO RICO	3	1.71%
SOMALIA	1	0.57%
TRUST TERRITORY	18	10.29%
UNITED STATES	67	38.29%
UNKNOWN	6	3.43%
VIETNAM	2	1.14%

**Table 3: 10-Year Cumulative Summary (2004-2013) of U.S. HD by Birth Country**

<b>Country of Birth</b>	<b>Number of Cases</b>	<b>Percent of Total Cases</b>
Missing	5	0.28%
AFGHANISTAN	1	0.06%
AMERICAN SAMOA	21	1.18%
ARGENTINA	1	0.06%
BAHAMAS	1	0.06%
BANGLADESH	7	0.39%
BOLIVIA	3	0.17%
BRAZIL	162	9.12%
BURMA	17	0.96%
BURUNDI	1	0.06%
CANADA	1	0.06%
CAPE VERDE	6	0.34%
CHINA	9	0.51%
COLOMBIA	14	0.79%
CONGO	1	0.06%
COSTA RICA	3	0.17%
CUBA	34	1.91%
DOMINICAN REPUBLIC	39	2.19%
ECUADOR	10	0.56%
EGYPT	2	0.11%
EL SALVADOR	2	0.11%
ENGLAND	1	0.06%
ETHIOPIA	13	0.73%
FIJI	2	0.11%
GAMBIA	1	0.06%
GERMANY	3	0.17%
GUAM	8	0.45%
GUATEMALA	4	0.23%
GUYANA	25	1.41%
HAITI	16	0.90%
INDIA	129	7.26%
INDONESIA	10	0.56%

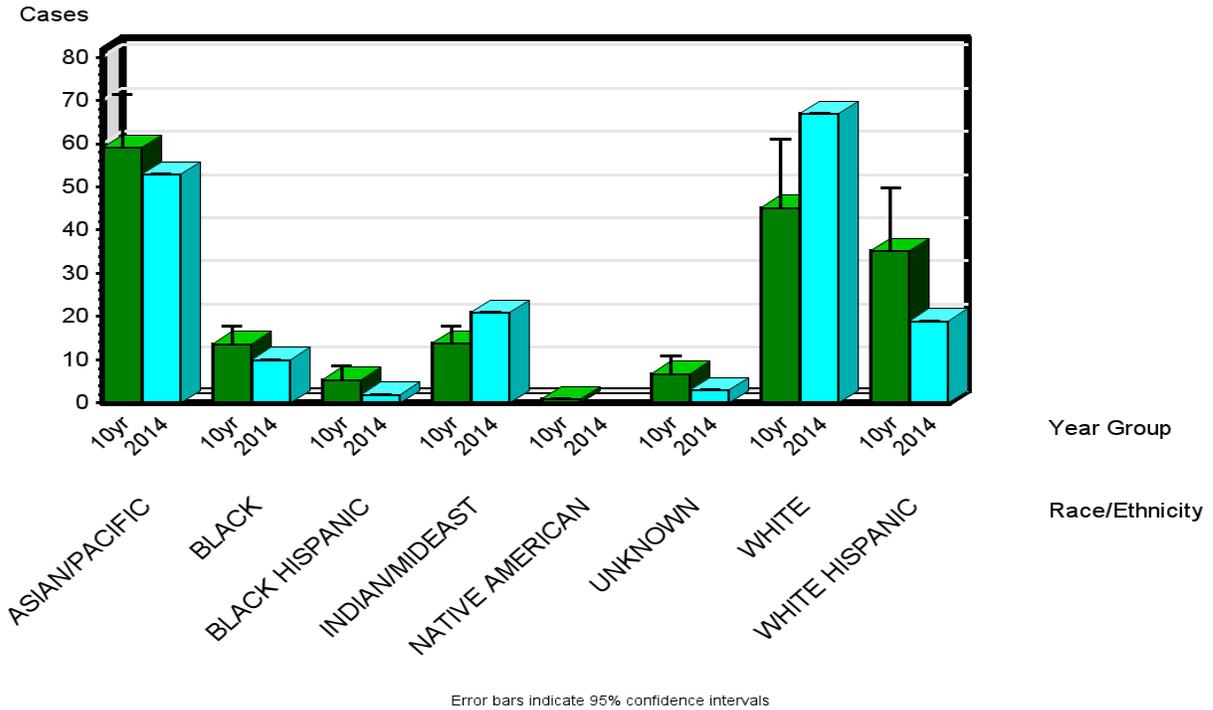
<b>Country of Birth</b>	<b>Number of Cases</b>	<b>Percent of Total Cases</b>
IRELAND	1	0.06%
ITALY	1	0.06%
IVORY COAST	2	0.11%
JAMAICA	3	0.17%
KAMPUCHEA	4	0.23%
KENYA	2	0.11%
KOREA	2	0.11%
LAOS	6	0.34%
LEBANON	1	0.06%
LIBERIA	6	0.34%
MEXICO	207	11.65%
MICRONESIA	161	9.06%
MOROCCO	1	0.06%
NEPAL	8	0.45%
NEW ZEALAND	1	0.06%
NIGERIA	10	0.56%
PAKISTAN	7	0.39%
PARAGUAY	4	0.23%
PHILIPPINES	132	7.43%
POLAND	1	0.06%
PUERTO RICO	34	1.91%
SIERRA LEONE	2	0.11%
SOMALIA	6	0.34%
SRI LANKA	3	0.17%
SUDAN	6	0.34%
SURINAME	2	0.11%
TANZANIA	1	0.06%
THAILAND	2	0.11%
TRINIDAD AND TOBAG	4	0.23%
TRUST TERRITORY	136	7.65%
UGANDA	1	0.06%
UNITED STATES	401	22.57%
UNKNOWN	23	1.29%
VENEZUELA	3	0.17%

<b>Country of Birth</b>	<b>Number of Cases</b>	<b>Percent of Total Cases</b>
<b>VIETNAM</b>	37	2.08%
<b>VIRGIN ISLANDS</b>	2	0.11%
<b>WESTERN SAMOA</b>	1	0.06%
<b>YUGOSLAVIA</b>	1	0.06%

**Table 4: 2014 U.S. Cases by Ethnicity Compared to Prior 10 years (2004-2013)**

Ethnicity	2014 Number of Cases	2014 Percent	Prior 10-Year Number of Cases	Prior 10-Year Percent
Missing	---	---	6	0.34%
AMERICAN INDIAN OR ALASKA NATIVE	---	---	1	0.06%
ASIAN OR PACIFIC ISLANDER	53	30.29%	592	33.31%
BLACK, NOT OF HISPANIC ORIGIN	10	5.71%	137	7.71%
HISPANIC, BLACK	2	1.14%	38	2.14%
HISPANIC, WHITE	19	10.86%	352	19.81%
INDIAN, MIDDLE EASTERNER	21	12.00%	138	7.77%
NOT SPECIFIED/UNKNOWN	3	1.71%	61	3.43%
WHITE, NOT OF HISPANIC ORIGIN	67	38.29%	452	25.44%

**Figure 4: U.S. HD Cases by Reported Ethnicity in 2014 Compared to Average seen per year in prior 10 years (2004-2013)**



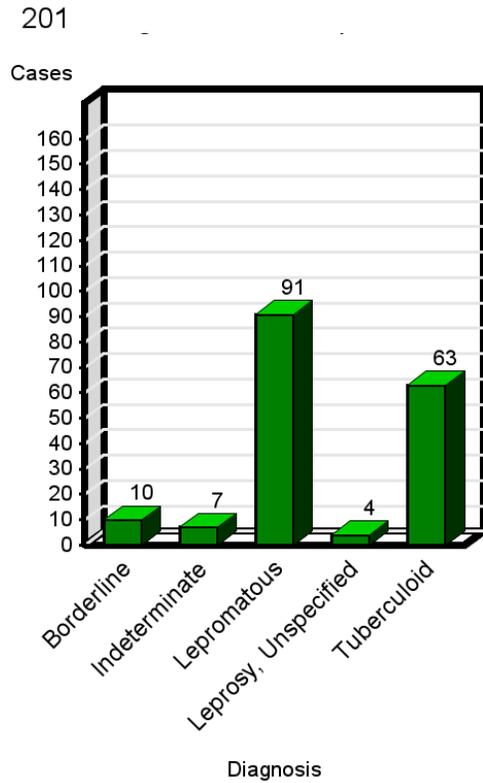
**Table 5: 2014 and Prior 10-Year Summary (2004-2013) of U.S. HD by Case Classification**

<b>Diagnosis Code HICFA</b>	<b>2014 Number of Cases</b>	<b>2014 Percent</b>	<b>Prior 10-Year Number of Cases</b>	<b>Prior 10-Year Percent</b>
Missing	---	---	30	1.69%
030.0	91	52.00%	985	55.43%
030.1	63	36.00%	497	27.97%
030.2	7	4.00%	77	4.33%
030.3	10	5.71%	124	6.98%
030.8	0	0%	9	0.51%
030.9	4	2.29%	55	3.10%

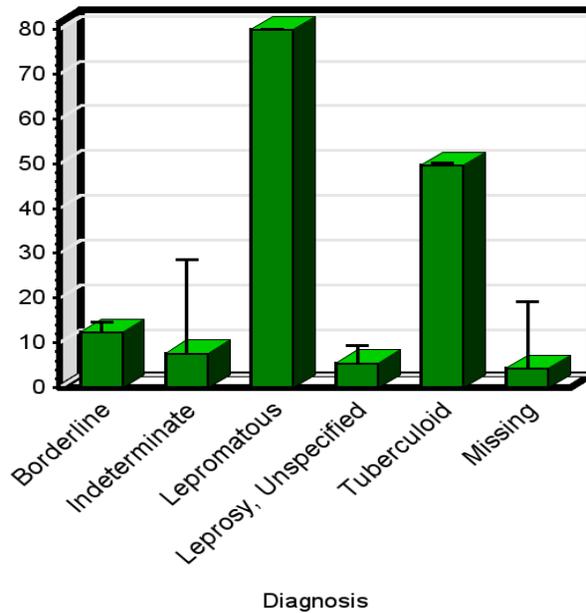
<b>WHO Classification</b>	<b>2014 Number of Cases</b>	<b>2014 Percent</b>	<b>Prior 10-Year Number of Cases</b>	<b>Prior 10-Year Percent</b>
Missing	5	2.85%	259	14.58%
MULTIBACILLARY	101	57.72%	943	53.07%
PAUCIBACILLARY	69	39.43%	575	32.36%

<b>Ridley-Jopling Classification</b>	<b>2014 Number of Cases</b>	<b>2014 Percent</b>	<b>Prior 10-Year Number of Cases</b>	<b>Prior 10-Year Percent</b>
Missing	2	1.14%	266	14.97%
BORDERLINE	10	5.71%	94	5.29%
BORDERLINE LEPROMATOUS	22	12.57%	222	12.49%
BORDERLINE TUBERCULOID	26	14.86%	232	13.06%
INACTIVE	3	1.71%	31	1.74%
INDETERMINATE	7	4.00%	79	4.45%
LEPROMATOUS LEPROSY	69	39.43%	652	36.69%
TUBERCULOID	36	20.57%	201	11.31%

**Figure 5a: 2014 U.S. HD Cases by Classification – Diagnosis Summary Statistics**

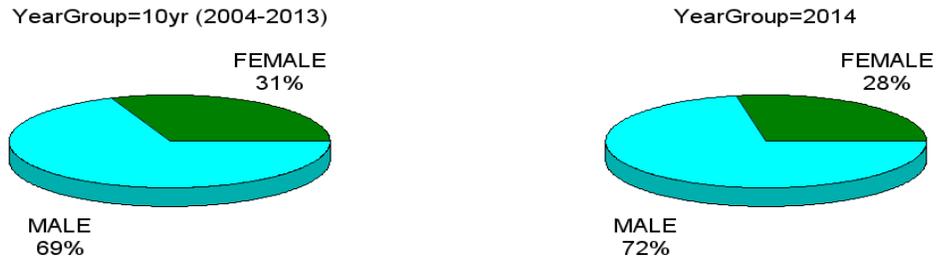


**Figure 5b: Prior 10-Year Summary (2004-2013) of U.S. HD Cases by Classification**



\*The Missing data category was present for 7 of the 10 years  
 Error bars indicate 95% confidence intervals

**Figure 6: Gender of U.S. HD Cases in 2014 and prior 10 years (2004-2013)**



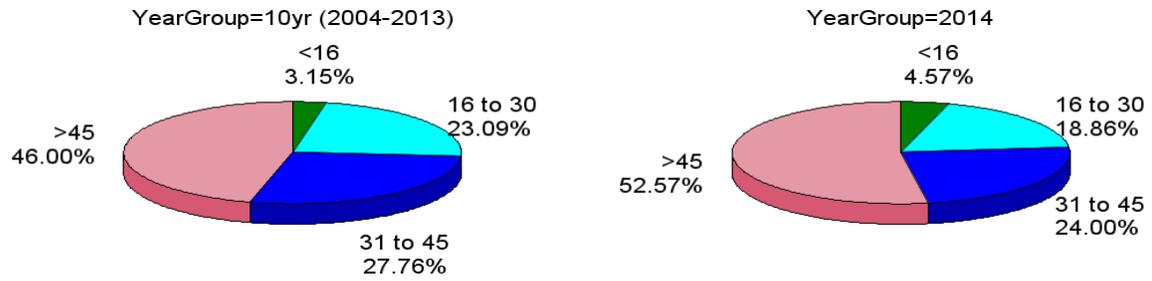
**Table 6: 2014 U.S. HD Cases by Gender Compared to Prior 10 Years (2004-2013)**

Gender	2014 Number of Cases	2014 Percent	Prior 10-Year Number of Cases	Prior 10-Year Percent
FEMALE	49	28%	550	30.95%
MALE	126	72%	1227	69.05%

**Table 7: 2014 U.S. HD Cases by Age Compared to Prior 10 Years (2004-2013)**

Age Group	2014 Number of Cases	2014 Percent	Prior 10-Year Number of Cases	Prior 10-Year Percent
Missing	---	---	1	0.06%
<16	8	4.57%	56	3.15%
16 to 30	33	18.86%	410	23.07%
31 to 45	42	24.00%	493	27.74%
>45	92	52.57%	817	45.98%

**Figure 7: 2014 U.S. HD Cases by Age Group percentage compared to prior 10 years (2004-2013)**



**Table 8a: 2014 U.S. HD Cases by Age and Gender**

Age Group	Number and Percent of Cases		
	FEMALE	MALE	Total
<16	3 1.71%	5 2.86%	8 4.57%
16 to 30	13 7.43%	20 11.43%	33 18.86%
31 to 45	8 4.57%	34 19.43%	42 24.00%
>45	25 14.29%	67 38.29%	92 52.57%
<b>Total</b>	49 28.00%	126 72.00%	175 100.00%

**Table 8b: 10-Year Summary (2004-2013) of U.S Cases by Age and Gender**

	<b>Number and Percent of Cases</b>		
<b>Age Group</b>	<b>FEMALE</b>	<b>MALE</b>	<b>Total</b>
<b>Missing</b>	1 0.06%	0 0.00%	1 0.06%
<b>&lt;16</b>	21 1.18%	35 1.97%	56 3.15%
<b>16 to 30</b>	118 6.64%	292 16.43%	410 23.07%
<b>31 to 45</b>	137 7.71%	356 20.03%	493 27.74%
<b>&gt;45</b>	273 15.36%	544 30.61%	817 45.98%
<b>Total</b>	549 30.95%	1227 69.05%	1777 100.00%