

A Summary of Hansen's Disease in the United States-2015

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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 patient information and maintains a National Hansen's Disease Registry (Registry). The Registry is a computerized database that provides operational information for administrative reports, program operational needs 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 acquired through delivery of the HD Surveillance Form, which serves as the instrument for processing new cases into the Registry. All information is handled with strict confidentiality and stored on NHDP server not connected to the internet. 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 de-identified data reported to the Registry (containing no personally identifiable information) 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 and customized reports addressing special data inquiries are provided to other governmental agencies and academic researchers as needed. The Registry is a record of basic demographic information on U.S. HD cases presented since 1894. The majority of all U.S. cases registered have presented since 1983. The total number of U.S. cases registered by the end of 2015 was 13,950. The following is a general demographic summary of the cases reported in the last decade through 2015.

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 reported by other agencies (Federal, state and local) to the Registry within a given calendar year is considered to be the 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, an operational definition of HD prevalence that reflects the total number of individuals potentially eligible for NHDP services is used and that number is estimated according to the likely life expectancy of all individuals recorded in the Registry.

A total of 178 cases were newly reported to the Registry in 2015. These additions are in keeping with the general trend of a slight increase 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.

A decline in annual case registrations was seen coincident to the relocation of the Program from Carville, Louisiana, to its current Baton Rouge campus in the late 1992. (Many physicians mistakenly thought the program had closed, and did not report cases). 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 13,950 HD cases have been registered in the U.S. since 1894. Based on estimates of life expectancy, some 9,140 of these cases are potentially still living and may be eligible for services from the NHDP for HD or HD-related medical care.

Geographic Distribution

HD cases were reported from 31 U.S. States and Puerto Rico in 2015 (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, Texas, Louisiana, Hawaii, and New York contributed the largest number of cases in 2015, and collectively accounted for 72 percent (129/178) of the cases registered. The predominance of these states is in keeping with the 10-year trend; more than 60 percent of reported cases arose in those same locations over the last decade.

Indigenous 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 2015, a total of 11 cases were reported from Hawaii and 3 from Puerto Rico. Reporting from Hawaii is in keeping with the historical trend; all 11 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 96 cases were reported from Texas (21), Louisiana (16), Arkansas (2), Mississippi (2), Alabama (2), Georgia (4), and Florida (49) 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 increase from 34 in 2014 to 49 cases in 2015. More than two-thirds (63/96) 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 178 reported cases, 101 (57 percent) recorded a location other than the U.S. as their place of birth. Collectively, national origin of the cases reported in 2015 could be associated with a total of 26 different countries (Table 2). Of those different birth countries reported, the largest numbers were born in the U.S. (77). Outside of the U.S., the South Pacific region continues to contribute the largest number of total cases including the Federated States of Micronesia (12), the Republic of the Philippines (12), and the Republic of the Marshall Islands (3). 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 Brazil, Cuba, or Vietnam (Table 3).

The WHO and allied non-government organizations (NGO's) have sponsored global campaigns for the "Elimination of Leprosy as a Public Health Problem" for some 30 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, the 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 2015 is shown in both 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 2015, the largest numbers of cases (43/178, 24 percent) identify themselves as being Asian or South Pacific Islanders. This continues a reversal of decadal trends and reflects the increasing number of cases being

reported among individuals from historical U.S. territories countries in the South Pacific. The largest individual racial group continues to be Whites (81/178, 45 percent).

Disease Classification

Leprosy manifests over a broad clinical and histopathological spectrum. The Ridley-Jopling classification system includes both the lepromatous and tuberculoid ends of the spectrum, as well as the associated borderline-lepromatous, mid-borderline, borderline-tuberculoid, and indeterminate classifications. This can be important in terms of prognosis and follow-up for potential untoward reactions. 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 2015, 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 (71/178) of U.S. cases are classified as lepromatous, and 24 percent (42/178) express borderline forms of the disease, while a similar number of cases are classified as tuberculoid (49/178, 27 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. Likewise, Paucibacillary cases can be identified by grouping the remaining categories. For 2015, 98/178 (55 percent) of the reported cases are grouped as Multibacillary and 77/178 (43 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 A), and illustrated graphically for 2015 in (Figures 5a) and for the preceding 10-year period in (Figure 5b).

Age and Gender

Of the 178 cases reported to the registry in 2015, 66 percent (117/178) were male and 34 percent (61/178) 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 2015 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 2015, the age of all registrants ranged from 7 to 95 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 and support services must be considered for patients of all age categories.

Conclusion

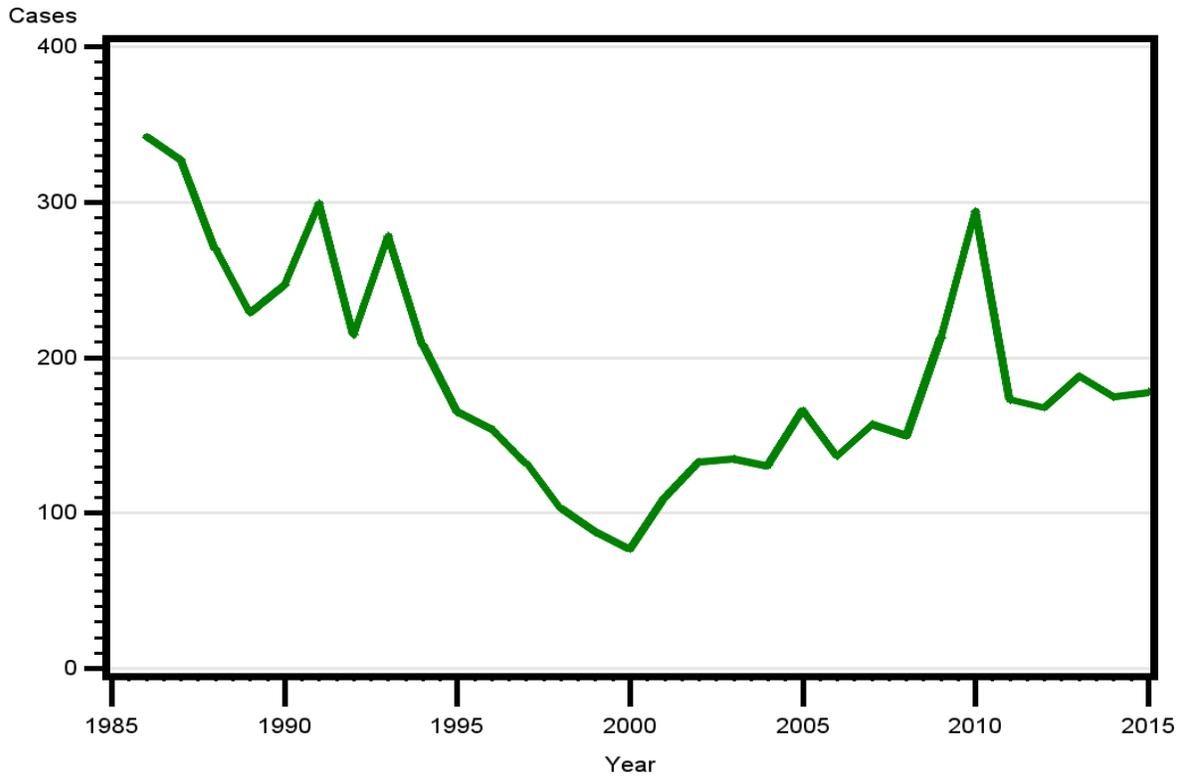
The number and type of new cases of Hansen's Disease reported in 2015, as well as their geographical origins and distribution within the U. S., are similar to the numbers seen for the previous decade. An increase in new cases has been seen in Florida in recent years. Although patients in the U. S. have origins in many different countries, the one country from which we receive the greatest number of new cases is the United States itself.

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Figure 1: U.S. Reported Hansen’s Disease Cases by Year 1985-2015



30-Year Data Table for Figure 1.					
Year	Number of Cases	Year	Number of Cases	Year	Number of Cases
1986	342	1996	154	2006	137
1987	327	1997	132	2007	157
1988	270	1998	103	2008	150
1989	229	1999	88	2009	213
1990	247	2000	77	2010	294
1991	299	2001	110	2011	173
1992	215	2002	133	2012	168
1993	278	2003	135	2013	188
1994	208	2004	131	2014	175
1995	165	2005	166	2015	178

Table 1a: 2015: U.S. HD Cases by Reporting Jurisdiction

2015 Reporting by Jurisdiction	Number of Cases	Percent of Total Cases
Alabama	3	1.69%
Arizona	2	1.12%
Arkansas	2	1.12%
California	22	12.36%
Delaware	1	0.56%
Florida	49	27.53%
Georgia	4	2.25%
Hawaii	11	6.18%
Illinois	1	0.56%
Kansas	1	0.56%
Kentucky	1	0.56%
Louisiana	16	8.99%
Maryland	2	1.12%
Massachusetts	5	2.81%
Michigan	1	0.56%
Minnesota	1	0.56%
Mississippi	2	1.12%
Missouri	1	0.56%
New York	10	5.62%
North Carolina	1	0.56%
Ohio	2	1.12%
Oklahoma	2	1.12%
Pennsylvania	3	1.69%
Puerto Rico	3	1.69%
South Carolina	1	0.56%
Texas	21	11.24%
Utah	1	0.56%
Vermont	1	0.56%

Virginia	2	1.12%
Washington	5	2.81%
Wisconsin	1	0.56%

Table 1b: 10-Year Cumulative Report (2005-2014) of U.S. Cases by Reporting Jurisdiction

Jurisdiction	Number of Cases	Percent of Total Cases
Missing	4	0.22%
Alabama	6	0.33%
Alaska	3	0.16%
Arizona	20	1.10%
Arkansas	52	2.86%
California	227	12.47%
Colorado	14	0.77%
Connecticut	12	0.66%
Delaware	1	0.05%
District of Columbia	3	0.16%
Florida	199	10.93%
Georgia	32	1.76%
Guam	1	0.05%
Hawaii	203	11.15%
Idaho	2	0.11%
Illinois	38	2.09%
Indiana	4	0.22%
Iowa	15	0.82%
Kansas	2	0.11%
Kentucky	5	0.27%
Louisiana	148	8.13%
Maine	1	0.05%
Maryland	17	0.93%

Massachusetts	118	6.48%
Michigan	8	0.44%
Minnesota	19	1.04%
Mississippi	20	1.10%
Missouri	18	0.99%
Montana	1	0.05%
Nebraska	5	0.27%
Nevada	11	0.60%
New Hampshire	1	0.05%
New Jersey	25	1.37%
New Mexico	5	0.27%
New York	146	8.02%
North Carolina	12	0.66%
Ohio	19	1.04%
Oklahoma	12	0.66%
Oregon	25	1.37%
Pennsylvania	24	1.32%
Puerto Rico	48	2.64%
Rhode Island	5	0.27%
South Carolina	7	0.38%
South Dakota	2	0.11%
Tennessee	6	0.33%
Texas	192	10.54%
Utah	13	0.71%
Vermont	2	0.11%
Virginia	11	0.60%
Washington	48	2.64%
West Virginia	1	0.05%
Wisconsin	8	0.44%

Figure 2: 2015 U.S. HD Cases by Reporting Jurisdiction

Figure 2: 2015 U.S. HD Cases by Reporting Jurisdiction

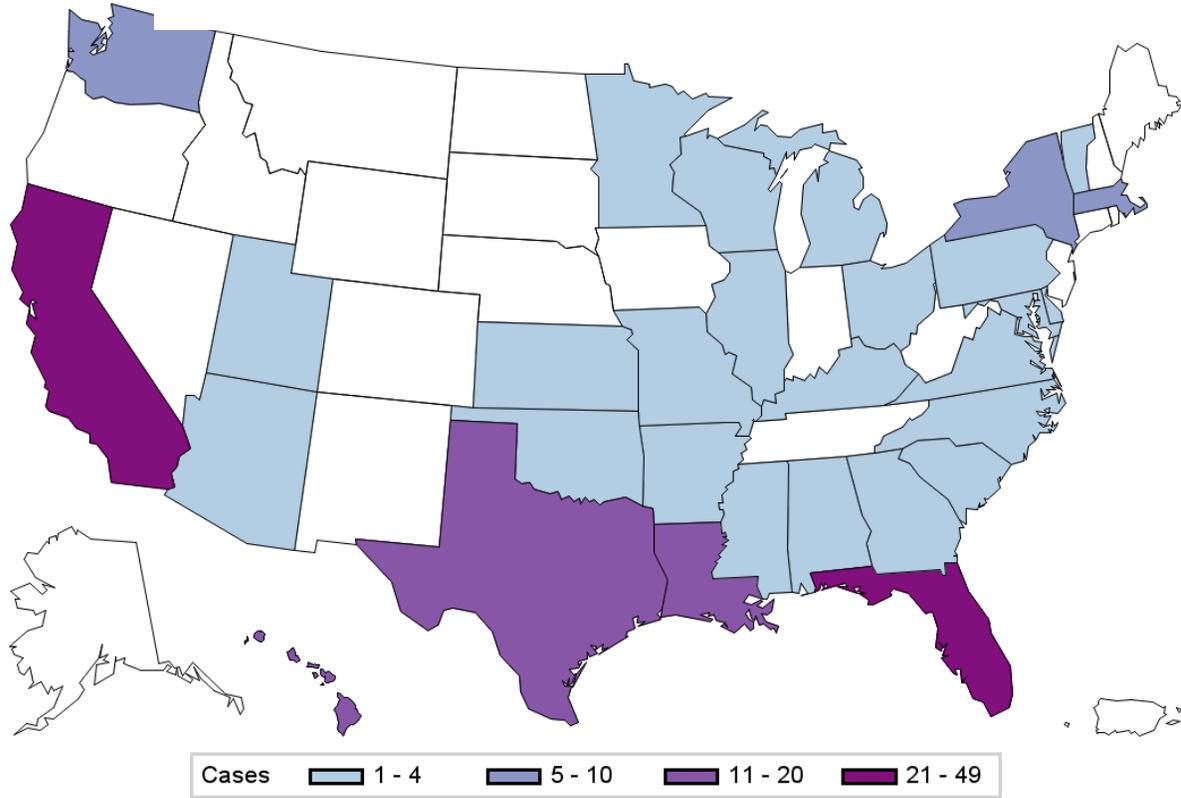


Figure 3: Average Number of HD Cases per Year (2005-2014) in the U.S. by Reporting Jurisdiction

10-Year Case Averages by Jurisdiction

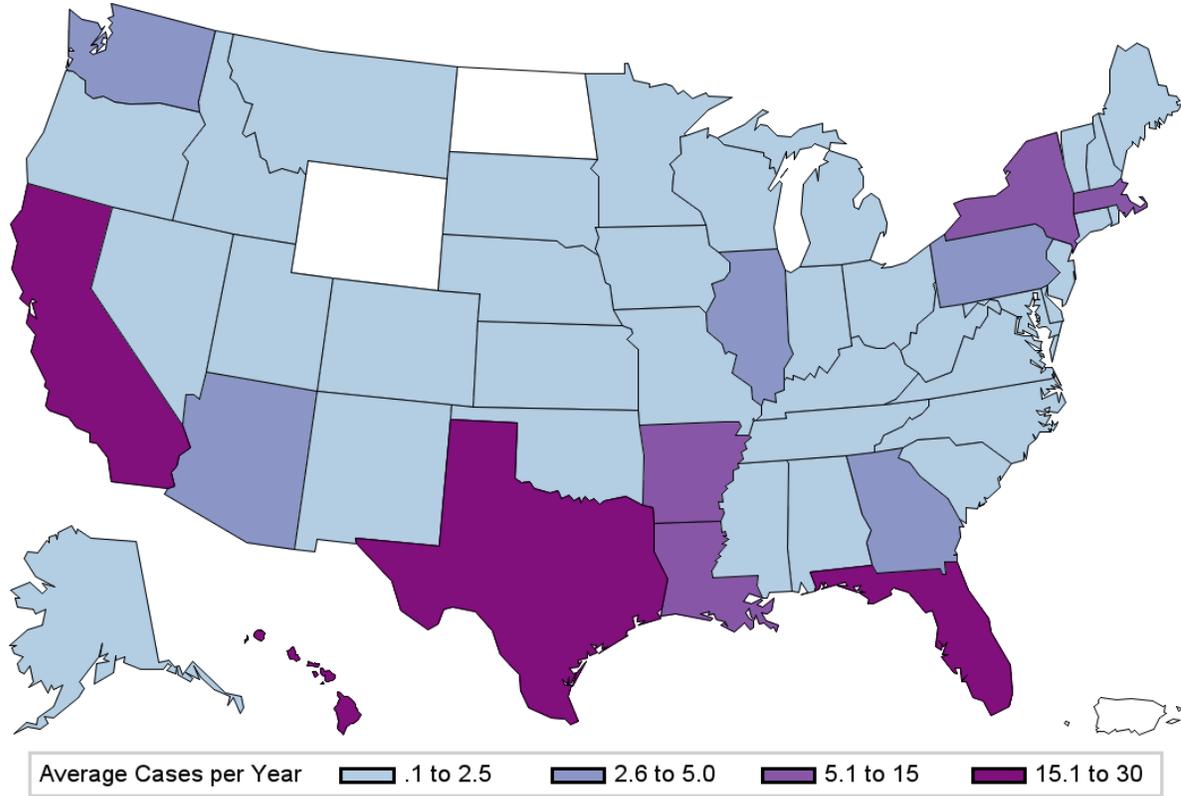


Table 2: 2015 U.S. HD Cases by Birth Country

Country of Birth	Number of Cases	Percent of Total Cases
Bhutan	2	1.12%
Brazil	4	2.25%
Burma	5	2.81%
Canada	1	0.56%
Cape Verde	1	0.56%
Colombia	1	0.56%
Costa Rica	1	0.56%
Cuba	3	1.69%
Dominican Republic	2	1.12%
Germany	2	1.12%
Ghana	1	0.56%
Guyana	1	0.56%
Haiti	2	1.12%
India	11	6.18%
Kampuchea	1	0.56%
Mexico	16	8.99%
Micronesia	12	6.74%
Mozambique	1	0.56%
Nepal	2	1.12%
Philippines	15	8.43%
Republic of the Marshall Islands	3	1.69%
Somalia	1	0.56%
St Lucia	1	0.56%
Trinidad and Tobago	2	1.12%
United States	77	43.26%
Unknown	7	3.93%
Vietnam	3	1.69%

Table 3: 10-Year Cumulative Reported (2005-2014) U.S. HD Cases by Birth Country

Country of Birth	Number of Cases	Percent of Total Cases
Missing	5	0.27%
Afghanistan	1	0.05%
Bahamas	1	0.05%
Bangladesh	7	0.38%
Bhutan	2	0.11%
Bolivia	3	0.16%
Brazil	156	8.57%
Burma	19	1.04%
Burundi	1	0.05%
Canada	1	0.05%
Cape Verde	5	0.27%
China	8	0.44%
Colombia	14	0.77%
Congo	2	0.11%
Costa Rica	3	0.16%
Cuba	30	1.65%
Dominican Republic	42	2.31%
Ecuador	8	0.44%
Egypt	3	0.16%
El Salvador	2	0.11%
England	1	0.05%
Ethiopia	13	0.71%
Fiji	2	0.11%
France	1	0.05%
Gambia	2	0.11%
Germany	3	0.16%
Guatemala	4	0.22%
Guyana	23	1.26%

Haiti	17	0.93%
India	142	7.80%
Indonesia	9	0.49%
Ireland	1	0.05%
Italy	1	0.05%
Ivory Coast	2	0.11%
Jamaica	3	0.16%
Kampuchea	4	0.22%
Kenya	2	0.11%
Korea	2	0.11%
Laos	5	0.27%
Lebanon	1	0.05%
Liberia	6	0.33%
Mexico	193	10.60%
Micronesia	160	8.79%
Morocco	1	0.05%
Nepal	9	0.49%
New Zealand	1	0.05%
Nigeria	7	0.38%
Pakistan	6	0.33%
Paraguay	4	0.22%
Philippines	131	7.19%
Poland	1	0.05%
Republic of the Marshall Islands	146	8.02%
Sierra Leone	2	0.11%
Somalia	6	0.33%
Sri Lanka	3	0.16%
Sudan	6	0.33%
Suriname	1	0.05%
Tanzania	1	0.05%
Thailand	2	0.11%
Trinidad and Tobago	4	0.22%

Uganda	1	0.05%
United States	507	27.83%
Unknown	29	1.59%
Venezuela	3	0.16%
Vietnam	36	1.98%
Virgin Islands	2	0.11%
Western Samoa	1	0.05%
Yugoslavia	1	0.05%

Table 4: 2015 U.S. Cases by Ethnicity Compared to Prior 10 years (2005-2014)

Ethnicity	2015 Number of Cases	2015 Percent	Prior 10-Year Number of Cases	Prior 10-Year Percent
Missing	---	---	6	0.34%
American Indian or Alaska Native	1	0.56%	1	0.05%
Asian or Pacific Islander	43	24.16%	600	32.95%
Black, Not of Hispanic Origin	14	7.87%	139	7.63%
Hispanic, Black	1	0.56%	36	1.98%
Hispanic, White	20	11.24%	308	16.91%
Indian, Middle Easterner	15	8.43%	153	8.40%
Not Specified/Unknown	3	1.69%	60	3.29%
White, Not of Hispanic Origin	81	45.51%	518	28.45%

Figure 4: U.S. HD Cases by Ethnicity in 2015 Compared to Average (2005-2014)

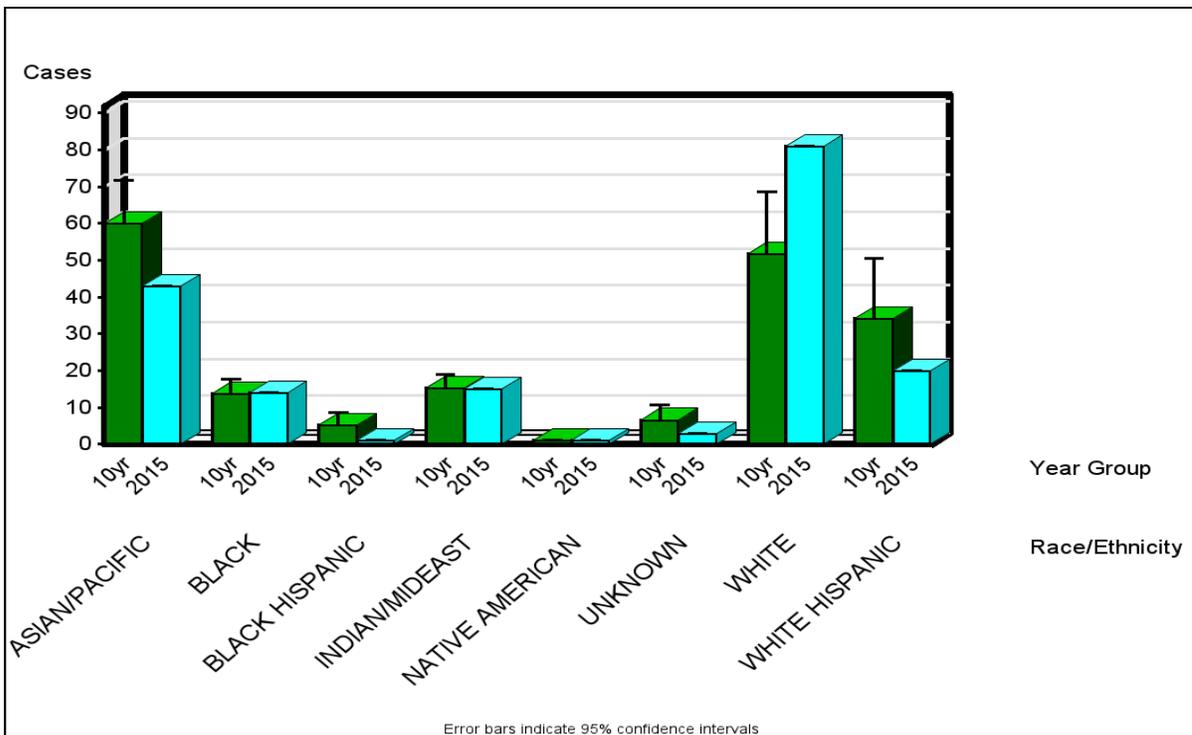


Table 5: 2015 and Prior 10-Year Cumulative Reported (2005-2014) U.S. HD Cases by Case Classification

WHO Classification	2015 Number of Cases	2015 Percent	Prior 10-Year Number of Cases	Prior 10-Year Percent
Missing	3	1.69%	149	8.18%
Multibacillary	98	55.06%	1031	56.62%
Paucibacillary	77	43.26%	641	35.20%

Ridley-Jopling Classification	2015 Number of Cases	2015 Percent	Prior 10-Year Number of Cases	Prior 10-Year Percent
Missing	6	3.37%	196	10.76%
Indeterminate	5	2.81%	83	4.56%
Tuberculoid	49	27.53%	232	12.74%
Borderline Tuberculoid	18	10.11%	250	13.73%
Borderline	9	5.06%	81	4.45%
Borderline Lepromatous	15	8.43%	238	13.07%
Lepromatous Leprosy	71	39.89%	707	38.82%
Inactive	5	2.81%	34	1.87%

Figure 5a: 2015 U.S. HD Cases by Classification – Diagnosis Summary Statistics

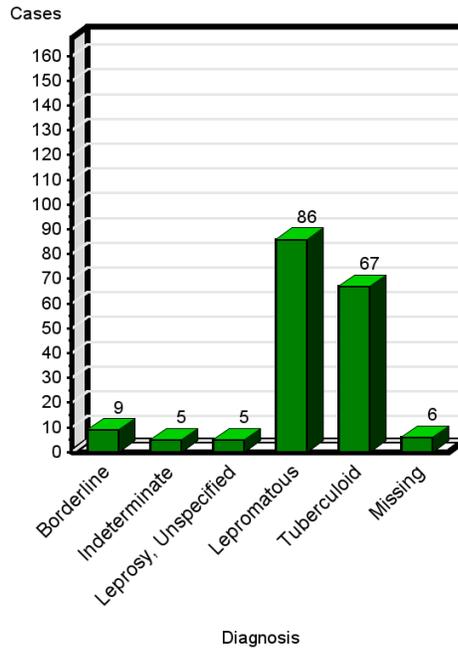
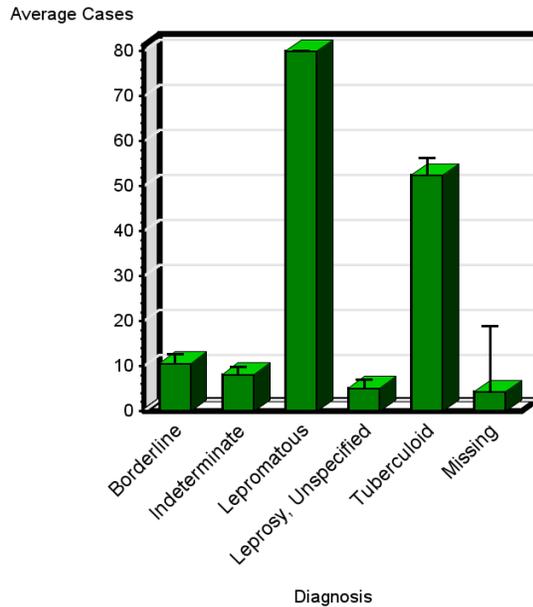


Figure 5b: Prior 10-Year Cumulative Reported (2005-2014) U.S. HD Cases by Classification



*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 2015 and Prior 10 years (2005-2014)

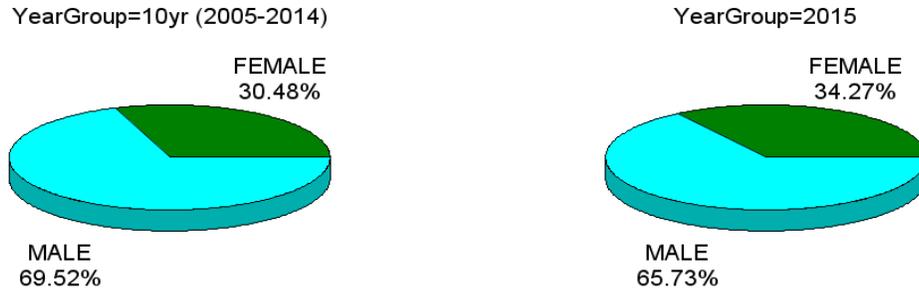


Table 6: 2015 U.S. HD Cases by Gender Compared to Prior 10 Years (2005-2014)

Gender	2015 Number of Cases	2015 Percent	Prior 10-Year Number of Cases	Prior 10-Year Percent
Female	61	34.27%	555	30.48%
Male	117	65.73%	1266	69.52%

Table 7: 2015 U.S. HD Cases by Age Compared to Prior 10 Years (2005-2014)

Age Group	2015 Number of Cases	2015 Percent	Prior 10-Year Number of Cases	Prior 10-Year Percent
Missing	---	---	1	0.05%
<16	4	2.25%	62	3.40%
16 to 30	31	17.42%	407	22.35%
31 to 45	38	21.35%	498	27.35%
>45	105	58.59%	853	46.84%

Figure 7: 2015 U.S. HD Cases by Age Group percentage compared to prior 10-years (2005-2014)

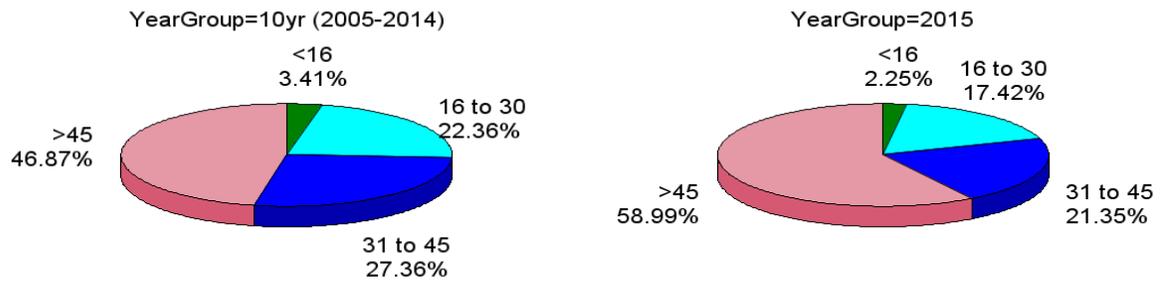


Table 8a: 2015 U.S. HD Cases by Age and Gender

Age Group	Number and Percent of Cases		
	Female	Male	Total
Missing	1 0.05%	0 0.00%	1 0.05%
<16	22 1.21%	40 2.20%	62 3.40%
16 to 30	118 6.48%	289 15.87%	407 22.35%
31 to 45	134 7.36%	364 19.99%	498 27.35%
>45	280 15.38%	573 31.47%	853 46.84%
Total	555 30.48%	1266 69.52%	1821 100.00%

Table 8b: 10-Year Cumulative Report (2005-2014) of U.S Cases by Age and Gender

Age Group	Number and Percent of Cases		
	Female	Male	Total
<16	1 0.56%	3 1.69%	4 2.25%
16 to 30	14 7.87%	17 9.55%	31 17.42%
31 to 45	8 4.49%	30 16.85%	38 21.35%
>45	38 21.35%	67 37.64%	105 58.99%
Total	61 34.27%	117 65.73%	178 100.00%