

A Summary of Hansen's Disease in the United States-2009

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



Introduction

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

HD 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, a 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 Web site at <http://www.hrsa.gov/hansensdisease/>. Registry data also is reported by various State and local government agencies through the same surveillance form.

HD is a federally notifiable disease, and data reported to the National HD Registry is shared with the Centers for Disease Control and Prevention (CDC), and the World Health Organization (WHO). In addition, summary reports or customized studies addressing special data inquiries are provided to other governmental agencies and qualified academic researchers as needed. The National Hansen's Disease 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 1981 (median year). The total number of U.S. cases registered by the end of 2009 was 12,685. The following is a general demographic summary of the cases reporting in 2009.

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Incidence and Prevalence of HD in the United States.

The NHDP derives operational values similar to epidemiological expressions of incidence and prevalence of HD in the United States from the HD 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 HD Registry.

A total of 213 cases were newly reported to the National Hansen's Disease Registry (NHDR) in 2009. This number is 63 more than was recorded in 2008 and reflects the addition of 43 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 our Program from Carville, Louisiana to its current Baton Rouge campus. Annual case registrations have generally increased since that time and may have been enhanced by our efforts to increase awareness of HD through several national seminars and scientific programs.

With this number of newly recorded cases a total of 12,685 Hansen's Disease cases have been registered in the United States since 1894. Based on estimates of life expectancy, some 7,078 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 our services each year and that summary of activity is not repeated here.

Geographic Distribution

HD cases were reported from 33 U.S. states (including Puerto Rico) in 2009 (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. California, Texas, Louisiana, New York, Hawaii, Florida, and Massachusetts contributed the largest number of cases in 2009, and collectively accounted for 65 percent (139/213) of the cases registered. The predominance of these States is in keeping with the 10 year trend in reporting, which also would identify Arkansas, Georgia, Illinois, Oregon, Pennsylvania, Washington and Puerto Rico as the most likely U.S. locations to report HD.

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 2009, a total of 33 cases were reported from Hawaii, and 7 from Puerto Rico. Reporting from Hawaii generally exceeds the historical trend and reflects enhanced reporting from that State. A total of 25 of those Hawaiian cases were among individuals who had come to Hawaii from U.S. Territories in the South Pacific.

A total of 42 cases were reported from Texas (26) and Louisiana (16). The combined number of cases is consistent with the historical norms from these States. About half (28/42) of all these cases were native born U.S. citizens with no residence history outside the United States, and reflects ongoing indigenous transmission within the population. HD has occurred in this region since the 1700s and recent evidence suggests that zoonotic transmission from the nine-banded armadillos is the principle source of infection perpetuating the infection in these locales.

National Origin

Of the 213 reported cases, 157 (74 percent) recorded a location other than the United States as their place of birth. Collectively, national origin of the cases reported in 2008 could be associated with a total of 29 different countries or territories (Table 2). Of the 29 different birth countries reported, the largest number (56) were US born or from U.S. Trust Territories (44), especially the Western Pacific Islands (42). These data highlight a recent trend for high rates of disease in these populations that began to emerge in the late 1960s and that 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 Viet Nam (Table 3).

The WHO (World Health Organization) 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 massive efforts, thousands of individual cases have been microbiologically cured of their disease. In 2008, the WHO reported that only 212,802 new cases were registered worldwide, representing a 4 percent decline in a single year and 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 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 we encounter in the United

States. 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 2009 is shown in Figure 4 and the associated Table 4. The 2009 distribution of ethnicities was in keeping with the 10 year trend and shows a broad involvement of ethnic groups. In 2009, the largest number of our cases (75/213, 35 percent) identify themselves as being Asian or Western Pacific Islanders. This reverses previous decadal trends and reflects the increasing number of cases being reported among individuals from U.S. Territories in the Western Pacific.

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 2009 is shown in Table 5 and depicted graphically in Figures 5a and 5b. The majority (184/213, 86 percent) of U.S. cases are coded as either 030.0 or 030.1 and correspond to either lepromatous (61 percent) or tuberculoid (26 percent) disease respectively. Comparing these percentages to the 10 year trend of reported codes shows no significant variation, and these 2009 diagnostic codings are in keeping with earlier observations.

Most leprologists 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 is frequently omitted from the 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 2009, and their 10 year trends, are shown in Table 5 section B and the accompanying figures. Consistent with the diagnosis code data nearly half (102/213) of U.S. cases are classified as lepromatous, but a roughly equivalent number (80/213) express borderline forms of the disease, while only 22 cases are seen as actual tuberculoid.

The WHO assesses cases only as “Multibacillary” or “Paucibacillary”. A category of Multibacillary cases can be created by combining the Borderline-lepromatous and Lepromatous classes from the ICM-9 codes. Likewise, Paucibacillary cases can be identified by grouping the remaining categories. For 2009 132/213 (62 percent) of the reported cases are grouped as Multibacillary and 72/213 (33 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 2009 in Figures 5a and for the preceding 10 year period in Figure 5b.

Age and Gender

Of the 213 cases reported to the registry in 2009, 70 percent (148/213) were male and 30 percent (65/213) 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 United States (Figure 6).

The age distribution of U.S. cases in 2007 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 2009, the age of all registrants ranged from 10 to 94 years. Obviously, the age of attack varies markedly within the United States, 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 CAPT Richard Truman, Ph.D

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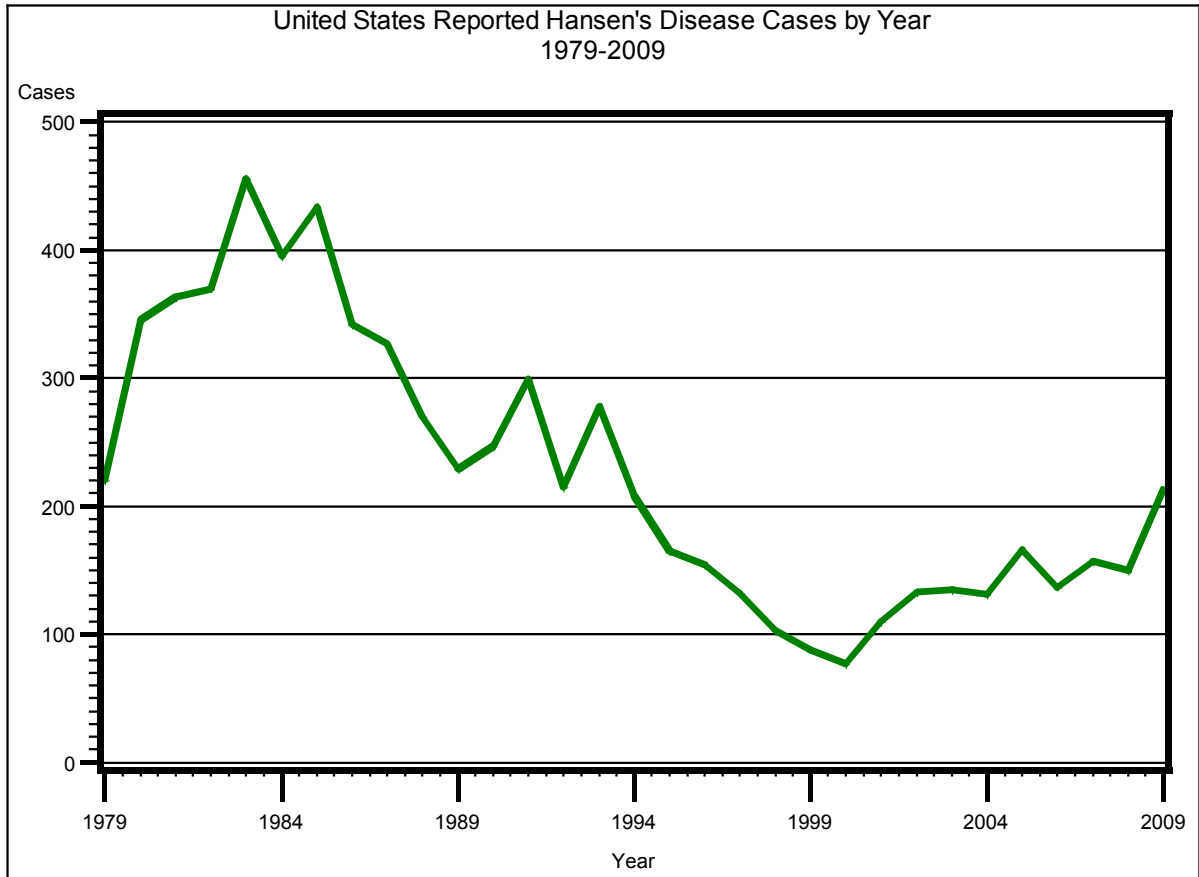
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Figure 1. U.S. Reported HD Cases by Year



30 Year Data Table	
Year	Frequency
1979	220
1980	346
1981	363
1982	370
1983	456
1984	395
1985	434
1986	342
1987	327
1988	270
1989	229
1990	247
1991	299
1992	215
1993	278
1994	208
1995	165
1996	154
1997	132
1998	103
1999	88
2000	77
2001	110
2002	133
2003	135
2004	131
2005	166
2006	137
2007	157
2008	150
2009	213

Table 1a: 2009 Summary of U.S. HD cases by Reporting State

State Reporting 2009	Frequency	Percent
Missing	1	0.47
ARKANSAS	7	3.29
CALIFORNIA	28	13.15
COLORADO	3	1.41
CONNECTICUT	1	0.47
DISTRICT OF COLUMBIA	3	1.41
FLORIDA	14	6.57
GEORGIA	4	1.88
HAWAII	33	15.49
ILLINOIS	4	1.88
IOWA	2	0.94
LOUISIANA	16	7.51
MASSACHUSETTS	22	10.33
MICHIGAN	2	0.94
MINNESOTA	2	0.94
MISSISSIPPI	3	1.41
MISSOURI	2	0.94
NEVADA	1	0.47
NEW HAMPSHIRE	1	0.47
NEW JERSEY	7	3.29
NEW YORK	4	1.88
OHIO	2	0.94
OKLAHOMA	1	0.47
OREGON	3	1.41
PENNSYLVANIA	3	1.41
PUERTO RICO	7	3.29
RHODE ISLAND	2	0.94
SOUTH CAROLINA	1	0.47
TENNESSEE	1	0.47
TEXAS	26	12.21
UTAH	2	0.94
VERMONT	2	0.94
VIRGINIA	1	0.47
WASHINGTON	2	0.94

Table 1b: Ten Year Summary of U.S. cases by Reporting State.

State Reporting 10 Year	Frequency	Percent
Missing	9	0.60
ALABAMA	3	0.20
ALASKA	2	0.13
ARIZONA	11	0.73
ARKANSAS	29	1.94
CALIFORNIA	235	15.70
COLORADO	12	0.80
CONNECTICUT	14	0.94
DELAWARE	1	0.07
DISTRICT OF COLUMBIA	4	0.27
FLORIDA	106	7.08
GEORGIA	23	1.54
HAWAII	123	8.22
IDAHO	5	0.33
ILLINOIS	28	1.87
INDIANA	4	0.27
IOWA	17	1.14
KANSAS	2	0.13
KENTUCKY	4	0.27
LOUISIANA	130	8.68
MAINE	1	0.07
MARYLAND	4	0.27
MASSACHUSETTS	83	5.54
MICHIGAN	8	0.53
MINNESOTA	12	0.80
MISSISSIPPI	11	0.73
MISSOURI	10	0.67
NEBRASKA	5	0.33
NEVADA	7	0.47
NEW HAMPSHIRE	2	0.13
NEW JERSEY	21	1.40
NEW MEXICO	3	0.20
NEW YORK	130	8.68
NORTH CAROLINA	4	0.27

State Reporting 10 Year	Frequency	Percent
OHIO	13	0.87
OKLAHOMA	6	0.40
OREGON	25	1.67
PENNSYLVANIA	30	2.00
PUERTO RICO	48	3.21
RHODE ISLAND	4	0.27
SOUTH CAROLINA	5	0.33
SOUTH DAKOTA	3	0.20
TENNESSEE	5	0.33
TEXAS	225	15.03
UTAH	11	0.73
VERMONT	2	0.13
VIRGINIA	8	0.53
WASHINGTON	44	2.94
WEST VIRGINIA	1	0.07
WISCONSIN	4	0.27

Figure 2: 2009 U.S. HD by Reporting State

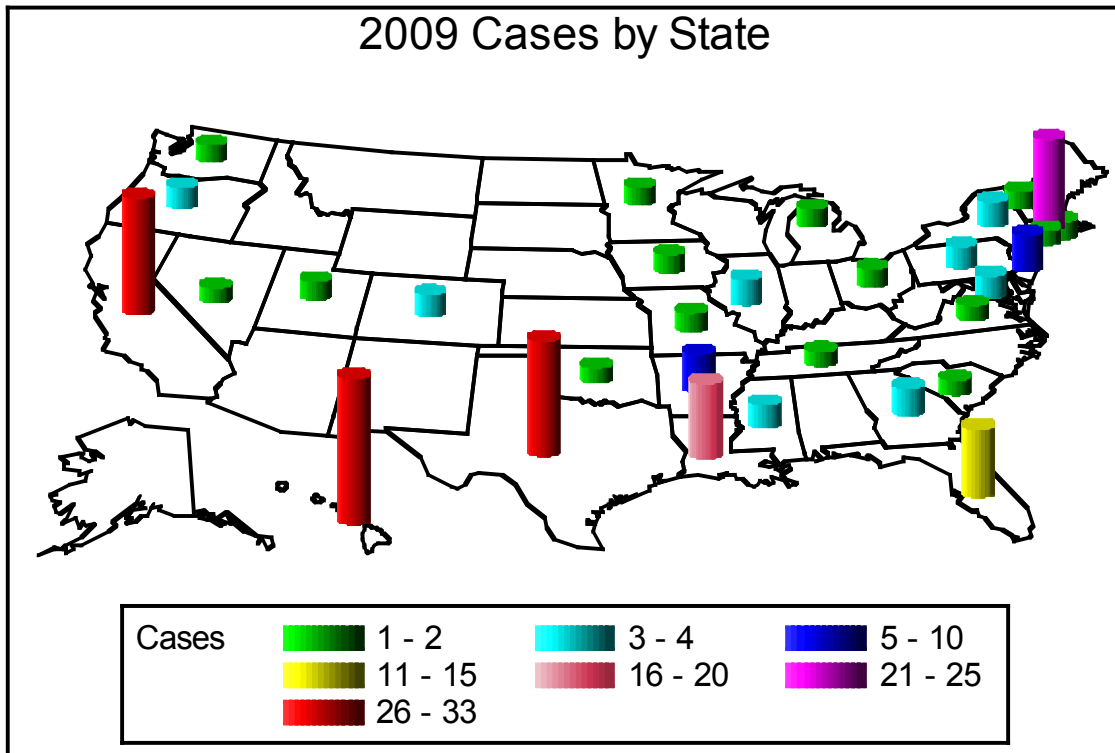


Figure 3: Cumulative Summaries of U.S. HD by Reporting State. Historical Summary of all reported cases since 1894 by county.

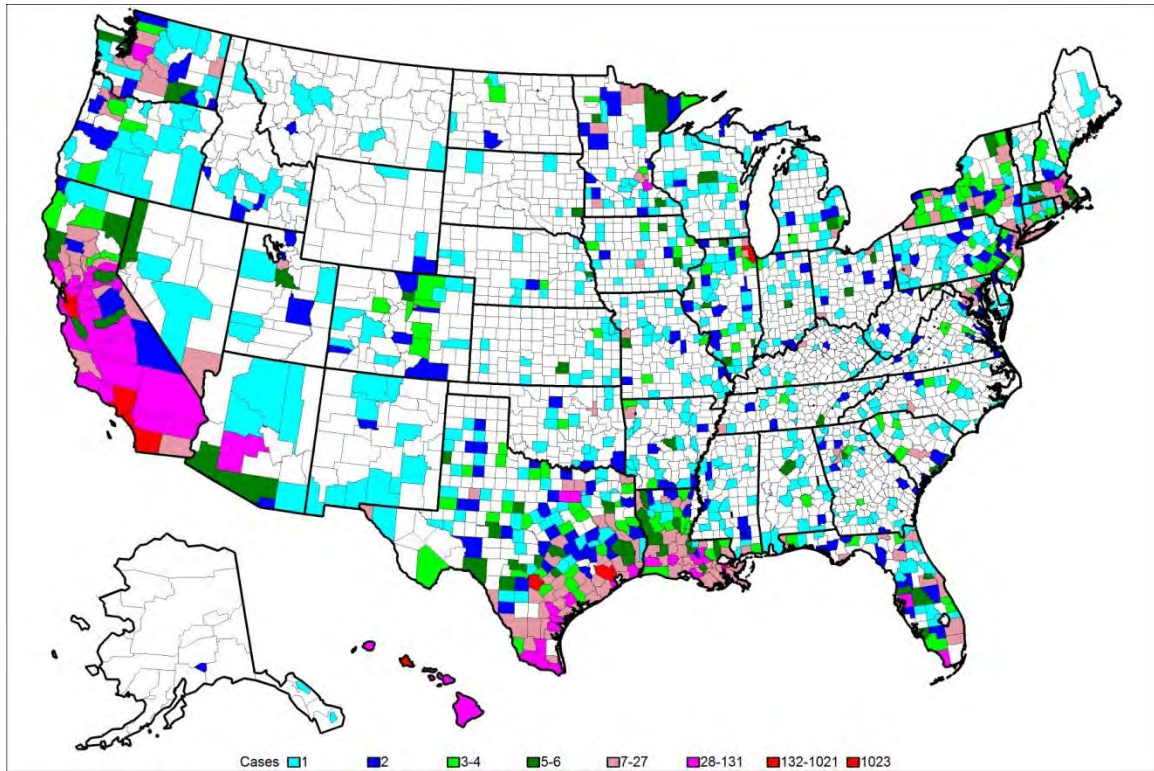


Table 2: 2009 U.S. HD cases by birth country.

Country of Birth 2009	Frequency	Percent
AMERICAN SAMOA #	2	0.94
BRAZIL	27	12.68
BURMA	1	0.47
CAPE VERDE	1	0.47
CHINA	1	0.47
COLOMBIA	1	0.47
CUBA	6	2.82
DOMINICAN REPUBLIC	3	1.41
EL SALVADOR	1	0.47
ETHIOPIA	2	0.94
GUAM *	1	0.47
GUYANA	2	0.94
HAITI	1	0.47
INDIA	15	7.04
INDONESIA	2	0.94
KAMPUCHEA	2	0.94
LIBERIA	2	0.94
MEXICO	16	7.51
MICRONESIA *	21	9.86
NEPAL	3	1.41
NIGERIA	2	0.94
PAKISTAN	1	0.47
PHILIPPINES	17	7.98
PUERTO RICO	4	1.88
SRI LANKA	1	0.47
TRUST TERRITORY *	17	7.98
UNITED STATES	56	25.82
VIETNAM	5	2.35

#= South Pacific *= Western Pacific

Table 3: Ten year cumulative summary of U.S. HD by birth country.

Country of Birth 10 Year Summary	Frequency	Percent
Missing	10	0.53
ALBANIA	1	0.07
AMERICAN SAMOA	14	0.94
ARGENTINA	1	0.07
BAHAMAS	1	0.07
BANGLADESH	4	0.27
BOLIVIA	1	0.07
BRAZIL	137	9.15
BURMA	8	0.53
BURUNDI	1	0.07
CAPE VERDE	4	0.27
CHILE	1	0.07
CHINA	7	0.47
COLOMBIA	13	0.87
CONGO	1	0.07
COSTA RICA	3	0.20
CUBA	42	2.81
DOMINICAN REPUBLIC	46	3.07
ECUADOR	7	0.47
EGYPT	2	0.13
EL SALVADOR	4	0.27
ENGLAND	1	0.07
ETHIOPIA	6	0.40
FIJI	1	0.07
GAMBIA	1	0.07
GUAM	3	0.20
GUATEMALA	3	0.20
GUYANA	15	1.00
HAITI	10	0.67
INDIA	115	7.68
INDONESIA	12	0.80
IRAN	1	0.07
ITALY	1	0.07
IVORY COAST	2	0.13
JAMAICA	3	0.20
JORDAN	1	0.07

Country of Birth 10 Year Summary	Frequency	Percent
KAMPUCHEA	6	0.40
KENYA	2	0.13
KOREA	1	0.07
LAOS	7	0.47
LEBANON	2	0.13
LIBERIA	4	0.27
MEXICO	227	15.16
MICRONESIA	85	5.68
NEPAL	3	0.20
NIGERIA	12	0.80
PAKISTAN	8	0.53
PARAGUAY	3	0.20
PHILIPPINES	125	8.35
POLAND	1	0.07
PUERTO RICO	31	2.07
SENEGAL	1	0.07
SOLOMON ISLANDS	1	0.07
SOMALIA	4	0.27
SRI LANKA	3	0.20
ST CHRISTOPHER NEVIS ST KITTS	1	0.07
SUDAN	8	0.53
SURINAME	2	0.13
TAIWAN	1	0.07
TANZANIA	1	0.07
THAILAND	2	0.13
TRINIDAD AND TOBAGO	7	0.47
TRUST TERRITORY	80	5.34
UGANDA	1	0.07
UNITED STATES	345	22.98
VENEZUELA	2	0.13
VIETNAM	33	2.20
VIRGIN ISLANDS	2	0.13
WESTERN SAMOA	3	0.20

Figure 4. U.S. HD cases by reported ethnicity.

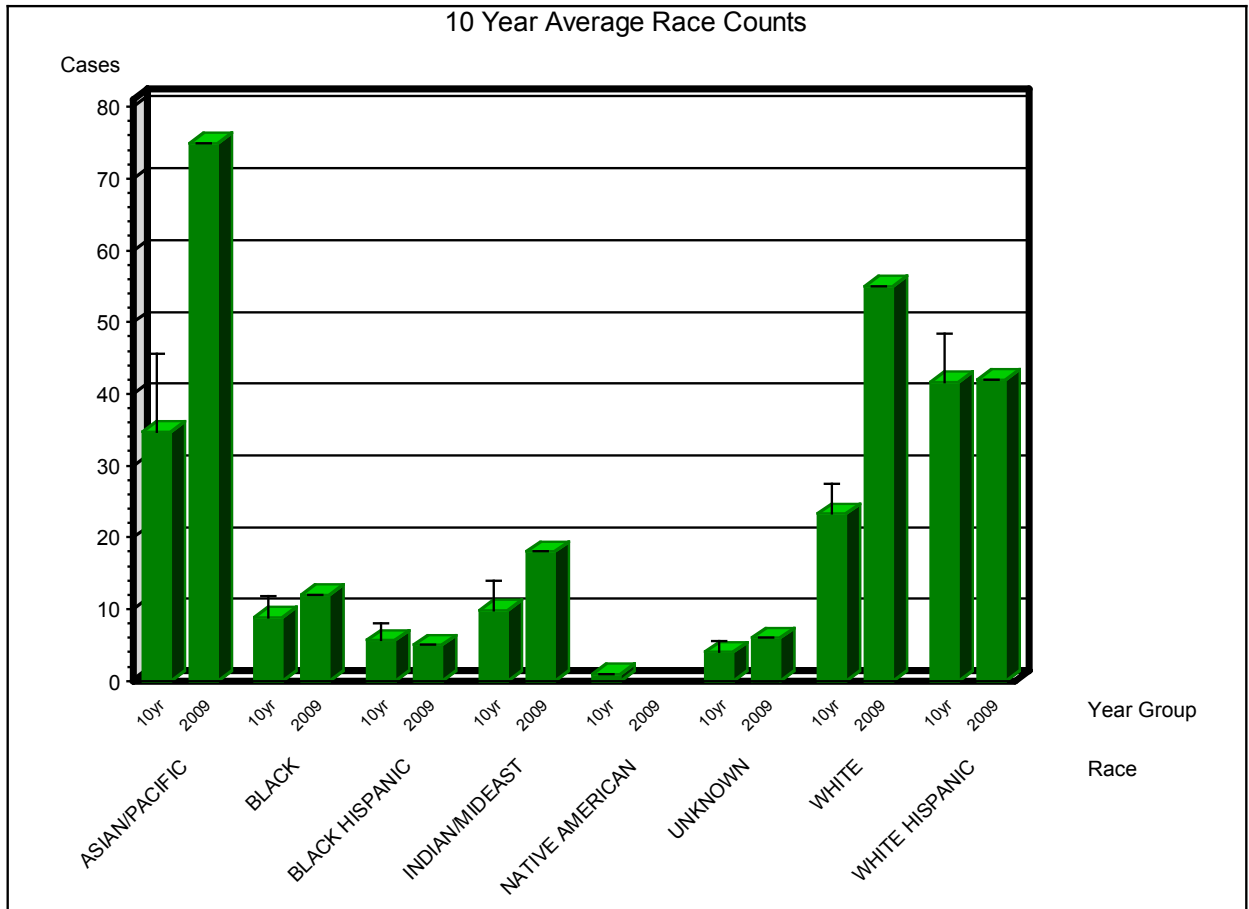


Table 4: 2009 and 10 year summary of U.S. cases by ethnicity.

Ethnicity	2009 Frequency	2009 Percent	10 Year Frequency	10 Year Percent
Missing	---	---	8	0.53
AMERICAN INDIAN OR ALASKA NATI	---	---	3	.20
ASIAN OR PACIFIC ISLANDER	75	35.21	423	28.26
BLACK, NOT OF HISPANIC ORIGIN	12	5.63	101	6.75
HISPANIC, BLACK	5	2.35	56	3.74
HISPANIC, WHITE	42	19.72	459	30.66
INDIAN, MIDDLE EASTERNER	18	8.45	117	7.82
NOT SPECIFIED/UNKNOWN	6	2.82	42	2.81
WHITE, NOT OF HISPANIC ORIGIN	55	25.82	288	19.24

Table 5: 2009 and 10 year summary of U.S. HD by case classification.

Diagnosis Code HICFA	2009 Frequency	2009 Percent	10 Year Frequency	10 Year Percent
Missing	1	0.47	6	0.40
030.0	129	60.56	831	55.51
030.1	55	25.82	373	24.92
030.2	8	3.76	62	4.14
030.3	14	6.57	159	10.62
030.8	---	---	6	.40
030.9	6	2.82	60	4.01

WHO Classification	2009 Frequency	2009 Percent	10 Year Frequency	10 Year Percent
Missing	10	8.4	538	35.94
MULTIBACILLARY	76	63.86	610	40.75
PAUCIBACILLARY	33	27.73	349	23.31

Ridley-Jopling Classification	2009 Frequency	2009 Percent	10 Year Frequency	10 Year Percent
Missing	7	3.29	303	20.24
Borderline	10	4.69	91	6.08
Borderline Lepromatous	30	14.08	181	12.09
Borderline Tuberculoid	33	15.49	187	12.49
Inactive	2	0.94	6	0.40
Indeterminate	7	3.29	66	4.41
Lepromatous Leprosy	102	47.89	542	36.21
Tuberculoid	22	10.33	121	8.08

Figure 5a: 2009 U.S. HD cases by classification

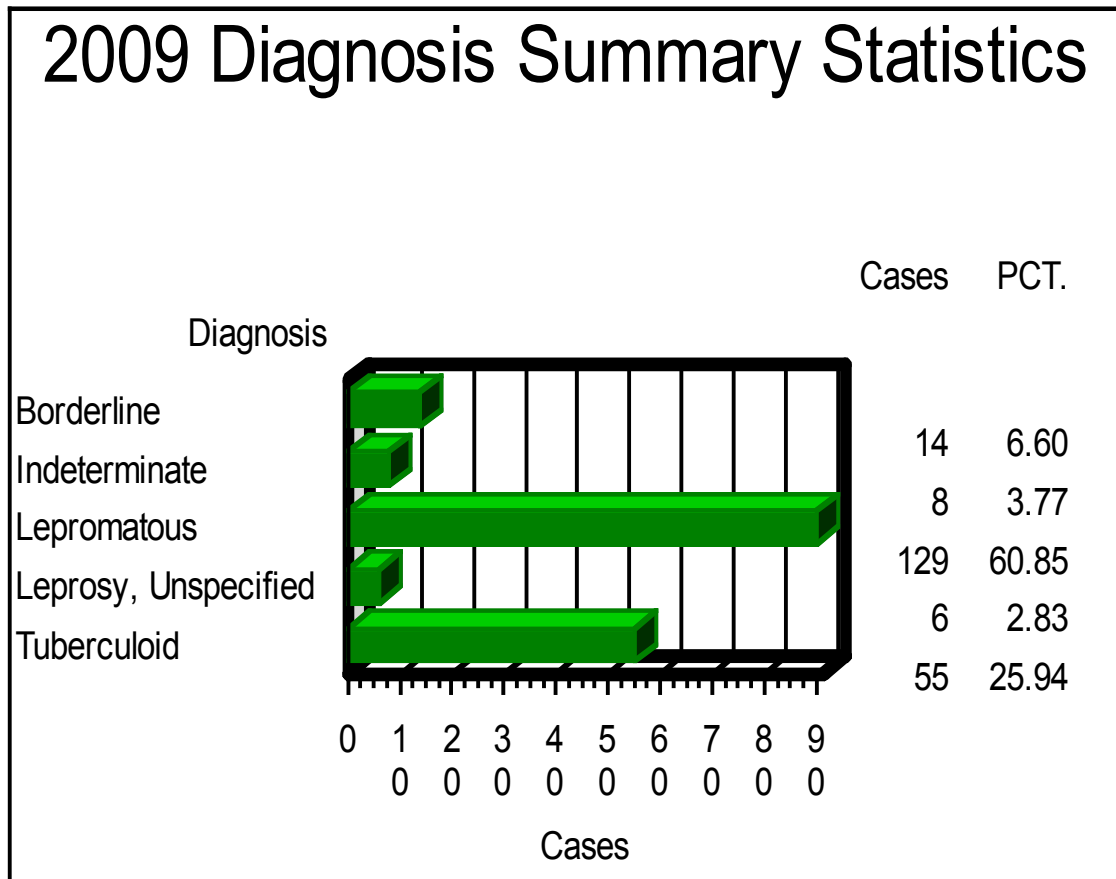


Figure 5B: Ten year summary of U.S. HD cases by classification.

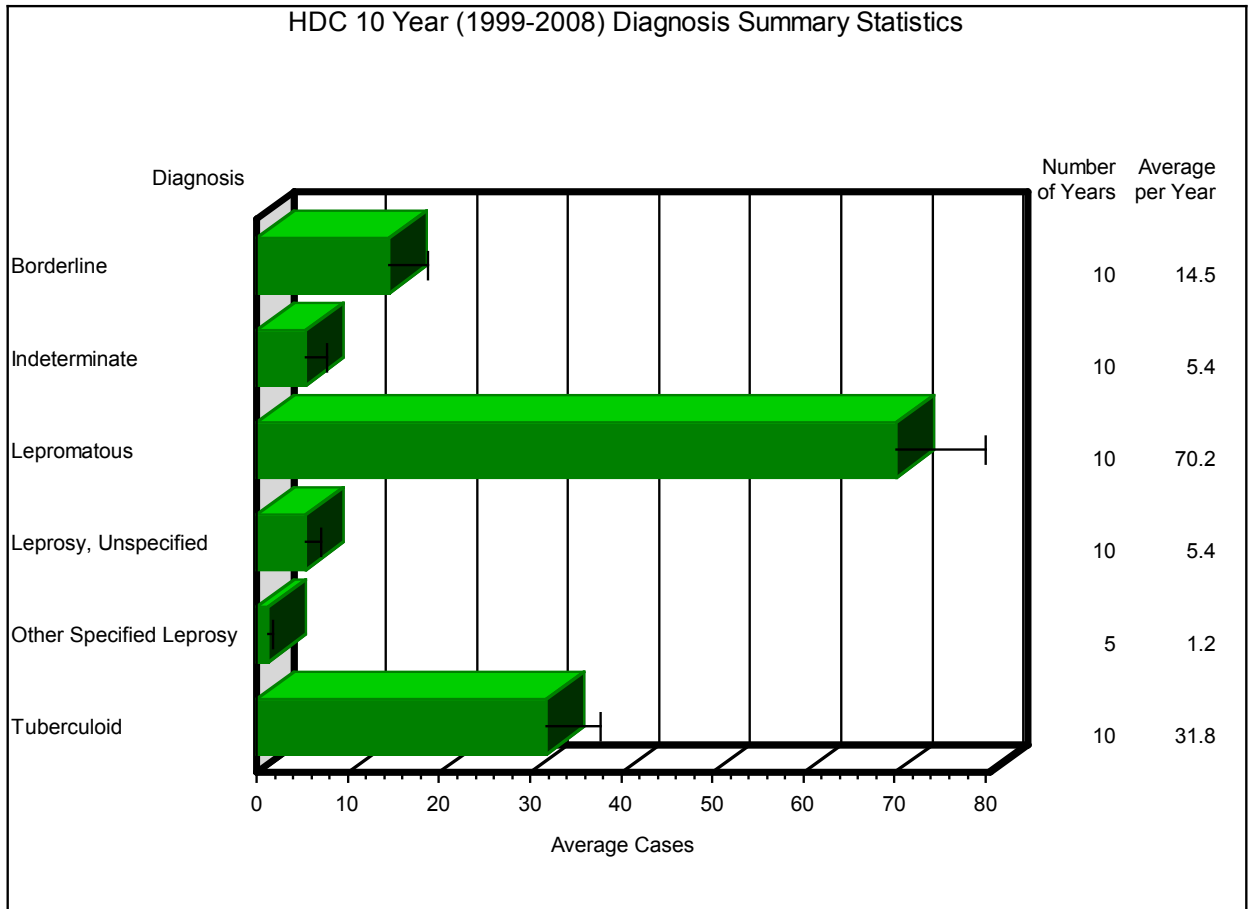


Figure 6: Gender of U.S. HD cases in 2009 and last 10 years.

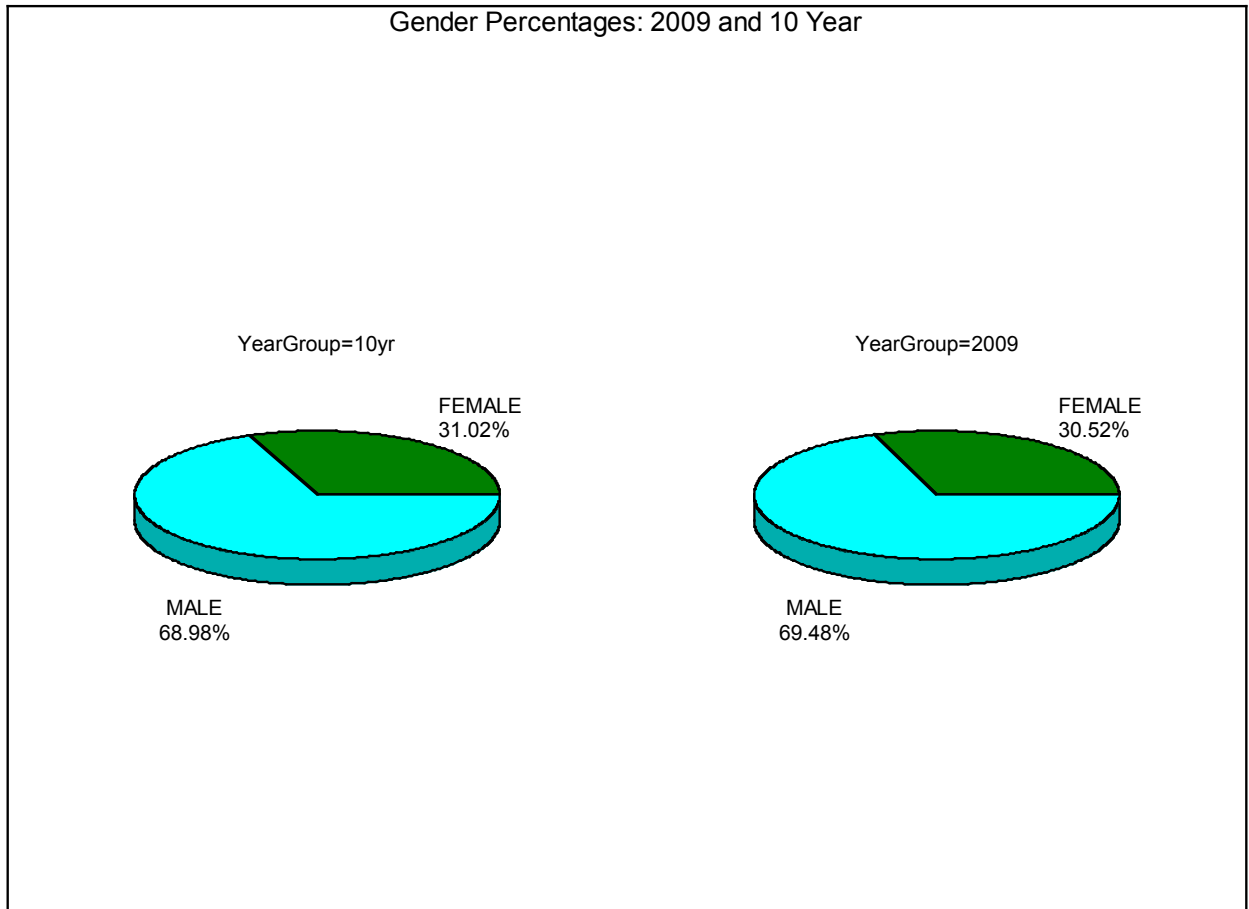


Table 6: 2009 and 10 year summary of U.S. HD cases by gender.

Gender	2009 Frequency	2009 Percent		
FEMALE	65	30.52		
MALE	148	69.48		

Table 7: 2009 and 10 year summary of U.S. HD cases by age.

Age Group	2009 Frequency	2009 Percent	10 Year Frequency	10 Year Percent
<16	7	3.29	1	0.07
16 to 30	48	22.54	45	3.01
31 to 45	60	28.17	365	24.38
>45	98	46.01	417	27.86

Figure 7: 2009 and 10 year summary of U.S. HD cases by age.

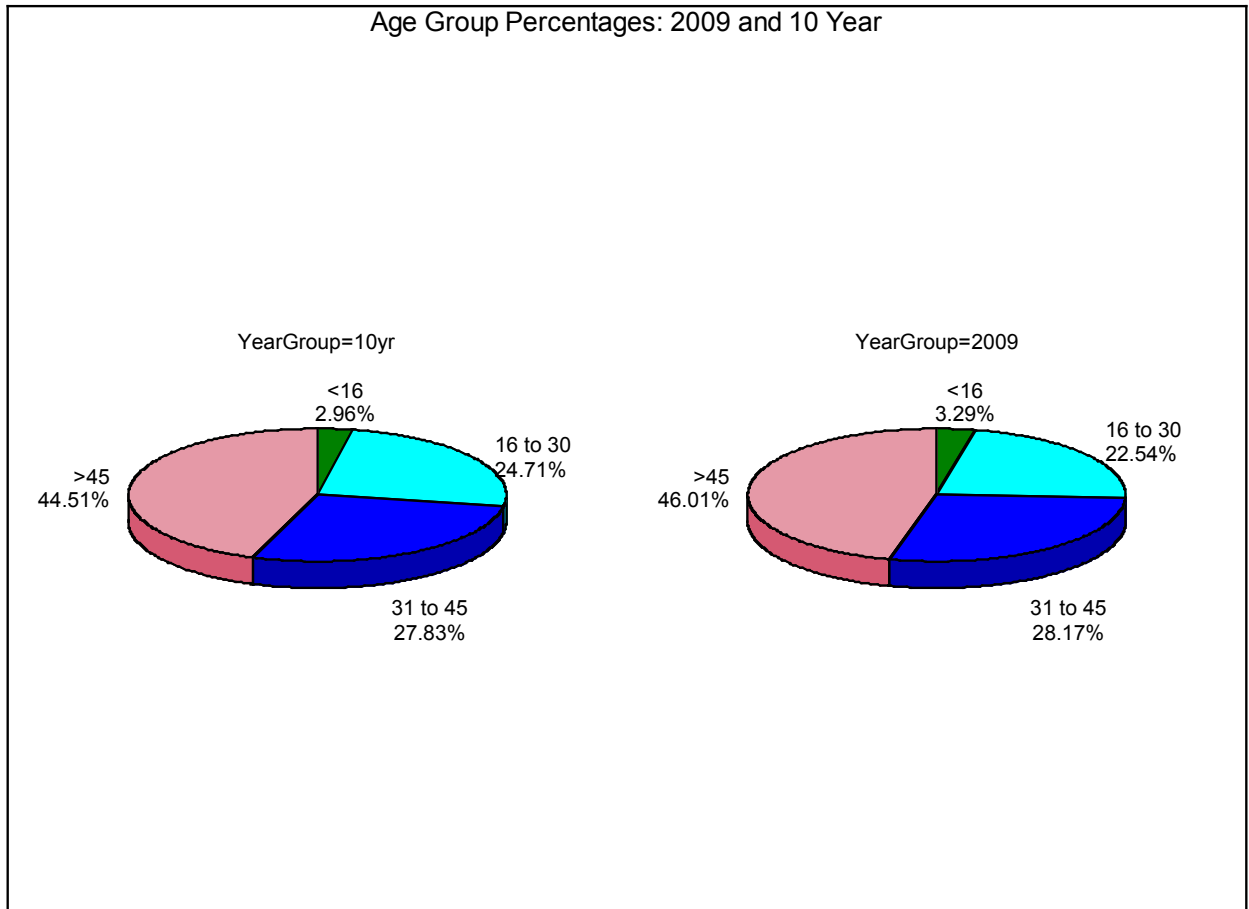


Table 8a: 2009 U.S. HD cases by age and gender.

Table of Age Group by Gender			
Age Group	Gender		Total
Frequency Percent	FEMALE	MALE	
<16	2 0.94	5 2.35	7 3.29
16 to 30	18 8.45	30 14.08	48 22.54
31 to 45	13 6.10	47 22.07	60 28.17
>45	32 15.02	66 30.99	98 46.01
Total	65 30.52	148 69.48	213 100.0 0

Table 8b: Ten year summary of U.S. cases by age and gender.

Table of Age Group by Gender				
Age Group	Gender			
Frequency Percent		FEMALE	MALE	Total
Missing	1 0.07	0 0.00	0 0.00	1 0.07
<16	0 0.00	19 1.27	26 1.74	45 3.01
16 to 30	0 0.00	110 7.35	255 17.03	365 24.38
31 to 45	0 0.00	112 7.48	305 20.37	417 27.86
>45	0 0.00	222 14.83	447 29.86	669 44.69
Total	1 0.07	463 30.93	1033 69.00	1497 100.00