

A Summary of Hansen's Disease in the United States-2008

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Introduction

The mission of HRSA'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/hansens/>. 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 2008 was 12,472. The following is a general demographic summary of the cases reporting in 2008.

Table of Contents:

Introduction	2
Table of Contents:.....	3
Incidence and Prevalence of HD in the US.	4
Geographic Distribution.....	4
National Origin.....	5
Race or Ethnicity	6
Disease Classification	6
Age and Gender	7
Contact Information:	8
Figure 1. U.S. Reported HD Cases by Year.....	9
Table 1a. 2008 Summary of U.S. HD cases by Reporting State.	10
Table 1b. Ten Year Summary of U.S. HD cases by Reporting State.	12
Figure 2. 2008 U.S. HD cases by Reporting State.	14
Figure 3. 10 Year Cumulative Summary of U.S. HD Cases by Reporting State...	15
Table 2. 2008 U.S. HD Cases by Birth Country.....	16
Table 3. Ten Year Cumulative Summary of U.S. HD Cases by Birth Country.....	18
Figure 4. U.S. HD Cases by Reported Ethnicity.....	21
Table 4. 2008 and Ten Year Cumulative Summary of U.S. HD Case Ethnicity...	21
Table 5. 2008 and 10 Year Summary of U.S. HD Case Classification	22
Figure 5a. 2008 U.S. HD Cases by Classification	23
Figure 5b. Ten Year Cumulative Summary of U.S. HD cases by Classification ..	24
Figure 6. Gender of U.S. HD Cases in 2008 and last 10 Years.....	25
Table 6. 2008 and Ten Year Cumulative Summary of U.S. HD Case Gender.	25
Table 7. 2008 and Ten Year Cumulative Summary of U.S. HD Cases by Age. ...	26
Table 8a. 2008 U.S. HD Cases by Age and Gender Distribution	27
Table 8b. Ten Year Cumulative Summary of Distribution of U.S. HD Cases by Age and Gender.....	28
Figure 7. 2008 and Ten Year Cumulative Summary of U.S. HD Cases by Age..	29

Incidence and Prevalence of HD in the US.

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 150 cases were newly reported to the National Hansen's Disease Registry (NHDR) in 2008. This number is 7 fewer than recorded in 2007 and is in keeping with the general trend in new case reporting 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 now have reverted to the historical mean.

With this number of newly recorded cases a total of 12,472 Hansen's Disease cases have been registered in the United States since 1894. Based on estimates of life expectancy, some 7,028 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.

In previous years, this report also documented the monthly registration of new cases. There is no pertinent epidemiological reason that a slow chronic disease might have variable reporting rates throughout the year, and these fluctuations in registration are wholly the result of internal operations. Although we do assess these data to identify backlogs in data recording or problems that individuals may have in documenting new cases, monthly registration data will no longer be posted in this report.

Geographic Distribution

HD cases were reported from 31 U.S. states (including Puerto Rico) in 2007 (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, Florida, Hawaii, Louisiana, Massachusetts, New York and Texas contributed the largest number of cases in 2008, and collectively accounted for 65 percent (97/150) 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, 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 2008, a total of 22 cases were reported from Hawaii, and 2 from Puerto Rico. Reporting from Hawaii generally exceeds the historical trend and reflects enhanced reporting from that State. A total of 16 of those Hawaiian cases were among individuals who had come to Hawaii from U.S. Territories in the South Pacific.

A total of 25 cases were reported from Texas (15) and Louisiana (10). The combined number of cases is consistent with the historical norms from these States. About half (11/25) 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 its relationship to transmission from the armadillo zoonotic reservoir is a topic of current investigation.

National Origin

Of the 150 reported cases, 122 (82 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 32 different countries or territories (Table 2). Of the 32 different birth countries reported, the largest numbers (59) were reported among individuals from Brazil (15), India (10), Mexico (19), and the Philippines (15). Another 30 cases arose from among individuals from the Trust Territories (17), Micronesia (12) or American or Western Samoa (1) reflecting a continuing high rate of disease in these populations that has begun 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.

Race or Ethnicity

The ethnic or racial association identified by cases reporting in 2007 is shown in Figure 4 and the associated Table 4. The 2007 distribution of ethnicities was in keeping with the 10 year trend and shows a broad involvement of ethnic groups. In 2008, the largest number of our cases (61/150, 40 percent) identify themselves as being Asian or South Pacific Islanders. This is a reversal of previous trends and reflects the increasing number of cases being reported among individuals from U.S. Territories in the South 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 2008 is shown in Table 5 and depicted graphically in Figures 5a and 5b. The majority (132/150, 88 percent) of U.S. cases are coded as either 030.0 or 030.1 and correspond to either lepromatous (70 percent) or tuberculoid (18 percent) disease respectively. Comparing these percentages to the 10 year trend of reported codes shows no significant variation, and these 2007 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 2007, and their 10 year trends, are shown in Table 5 section B and the accompanying figures. Consistent with the diagnosis code data nearly half (74/150) of U.S. cases are classified a lepromatous, but a roughly equivalent number (54/150) express borderline forms of the disease, while only 9 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 2007, 73 (53 percent) of the reported cases are grouped as Multibacillary and 61 (45 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 2007 in Figures 5a and for the preceding 10 year period in Figure 5b.

Age and Gender

Of the 150 cases reported to the registry in 2008, 72 percent (107/150) were male and 28 percent (43/150) 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 2007, the age of all registrants ranged from 10 to 82 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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Figure 1. U.S. Reported HD Cases by Year

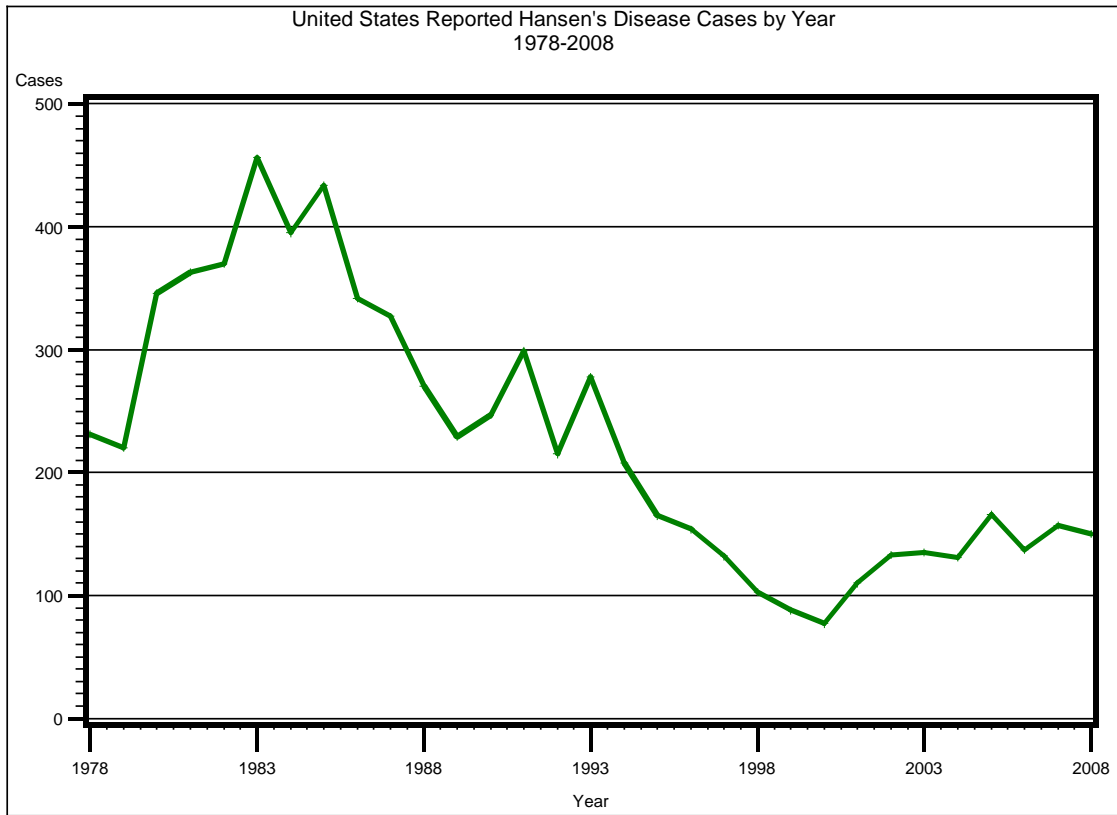


Table 1a. 2008 Summary of U.S. HD cases by Reporting State

State Reporting	2008 Frequency	2008 Percent
ARIZONA	4	2.67
CALIFORNIA	18	12.00
COLORADO	1	0.67
CONNECTICUT	3	2.00
FLORIDA	13	8.67
GEORGIA	3	2.00
HAWAII	22	14.67
ILLINOIS	7	4.67
IOWA	2	1.33
LOUISIANA	10	6.67
MARYLAND	1	0.67
MASSACHUSETTS	9	6.00
MINNESOTA	1	0.67
MISSISSIPPI	1	0.67
MISSOURI	3	2.00
NEBRASKA	1	0.67
NEVADA	1	0.67
NEW JERSEY	3	2.00
NEW MEXICO	1	0.67
NEW YORK	10	6.67
OHIO	2	1.33
OKLAHOMA	1	0.67
OREGON	1	0.67
PENNSYLVANIA	4	2.67
PUERTO RICO	2	1.33
SOUTH CAROLINA	1	0.67
SOUTH DAKOTA	1	0.67
TEXAS	15	10.00

State Reporting	2008 Frequency	2008 Percent
UTAH	3	2.00
WASHINGTON	5	3.33
WISCONSIN	1	0.67

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

State Reporting	10 Year Cumulative Frequency	10 Year Cumulative Percent
Missing	18	1.18
ALABAMA	4	0.26
ALASKA	2	0.13
ARIZONA	13	0.86
ARKANSAS	24	1.58
CALIFORNIA	268	17.64
COLORADO	9	0.59
CONNECTICUT	14	0.92
DELAWARE	1	0.07
DISTRICT OF COLUMBIA	1	0.07
FLORIDA	104	6.85
GEORGIA	21	1.38
HAWAII	114	7.50
IDAHO	5	0.33
ILLINOIS	25	1.65
INDIANA	4	0.26
IOWA	16	1.05
KANSAS	2	0.13
KENTUCKY	4	0.26
LOUISIANA	126	8.29
MAINE	1	0.07
MARYLAND	5	0.33
MASSACHUSETTS	61	4.02
MICHIGAN	7	0.46
MINNESOTA	10	0.66
MISSISSIPPI	8	0.53
MISSOURI	9	0.59
NEBRASKA	6	0.39

State Reporting	10 Year Cumulative Frequency	10 Year Cumulative Percent
NEVADA	6	0.39
NEW HAMPSHIRE	1	0.07
NEW JERSEY	14	0.92
NEW MEXICO	3	0.20
NEW YORK	154	10.14
NORTH CAROLINA	4	0.26
OHIO	11	0.72
OKLAHOMA	5	0.33
OREGON	26	1.71
PENNSYLVANIA	29	1.91
PUERTO RICO	49	3.23
RHODE ISLAND	2	0.13
SOUTH CAROLINA	4	0.26
SOUTH DAKOTA	4	0.26
TENNESSEE	7	0.46
TEXAS	248	16.33
UTAH	9	0.59
VIRGINIA	8	0.53
WASHINGTON	47	3.09
WEST VIRGINIA	1	0.07
WISCONSIN	5	0.33

Figure 2. 2008 U.S. HD cases by Reporting State

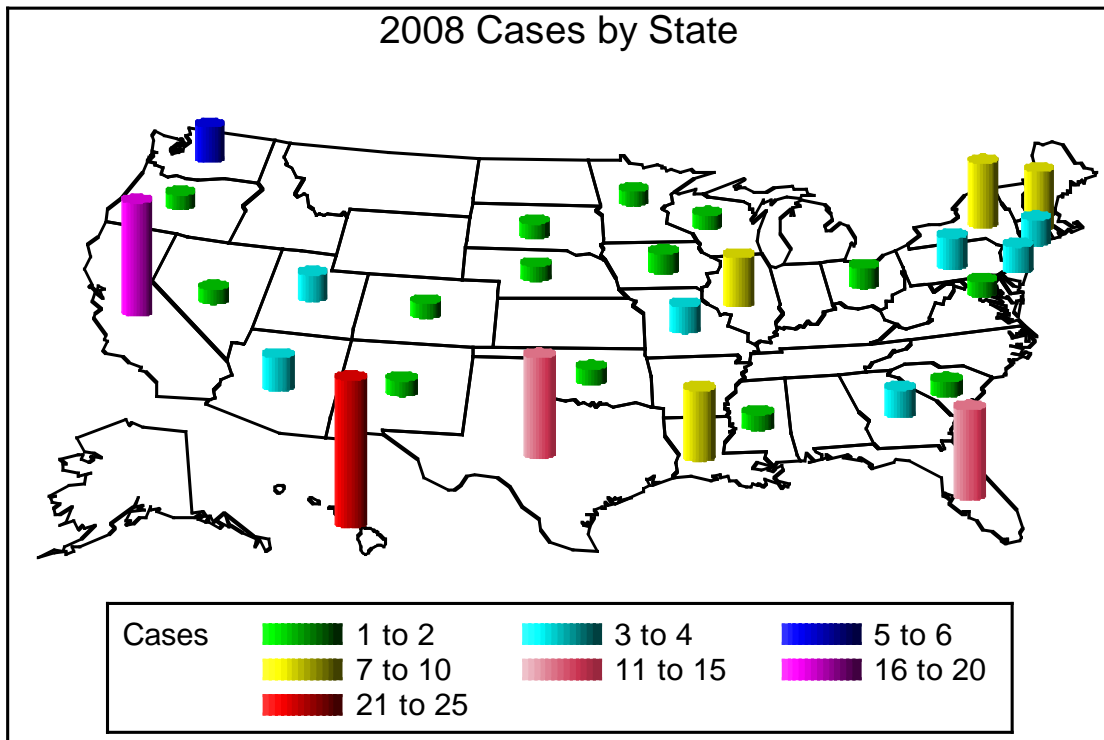


Figure 3. 10 Year Cumulative Summary of U.S. HD Cases by Reporting State

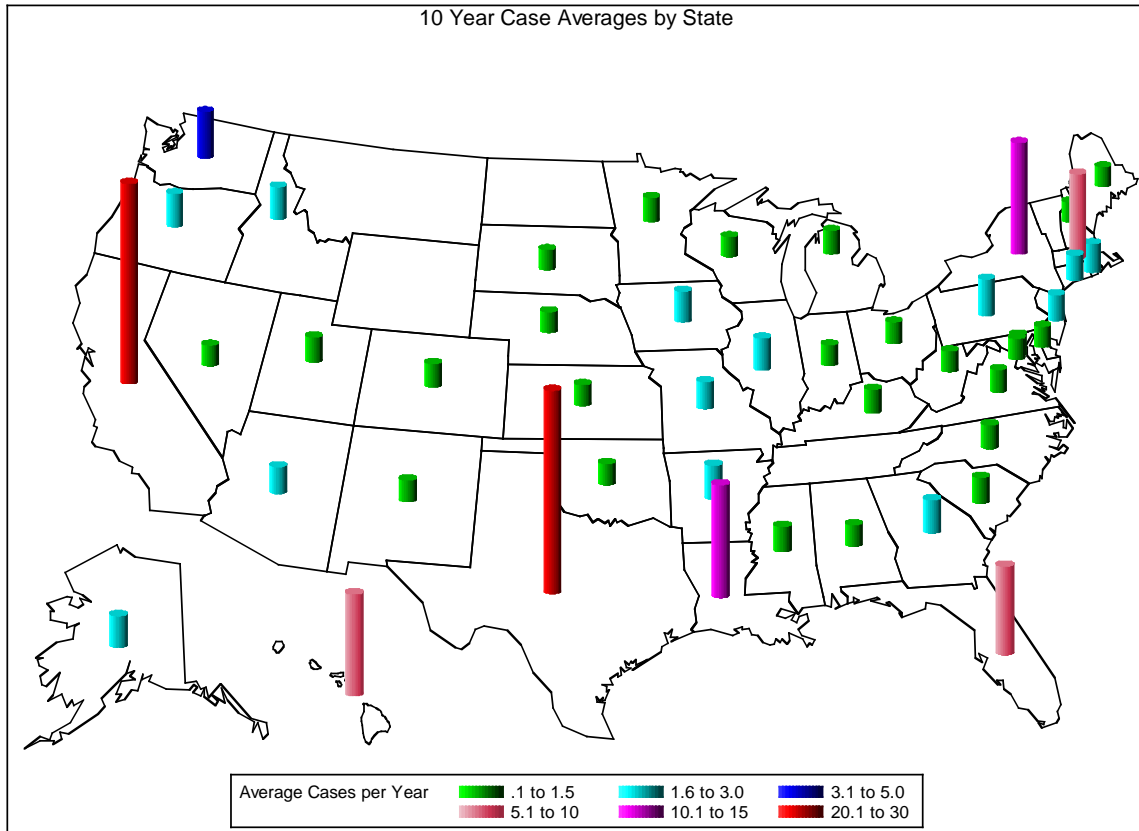


Table 2. 2008 U.S. HD Cases by Birth Country

Country of Birth	2008 Frequency	2008 Percent
AMERICAN SAMOA	1	0.67
BRAZIL	15	10.00
BURMA	2	1.33
CAPE VERDE	1	0.67
CHINA	1	0.67
COLOMBIA	1	0.67
CUBA	2	1.33
DOMINICAN REPUBLIC	4	2.67
ECUADOR	1	0.67
EGYPT	1	0.67
ENGLAND	1	0.67
ETHIOPIA	3	2.00
GUAM	2	1.33
GUATEMALA	1	0.67
GUYANA	2	1.33
HAITI	1	0.67
INDIA	10	6.67
ITALY	1	0.67
IVORY COAST	1	0.67
LEBANON	1	0.67
MEXICO	19	12.67
MICRONESIA	12	8.00
PAKISTAN	1	0.67
PARAGUAY	1	0.67
PHILIPPINES	15	10.00
SUDAN	1	0.67
THAILAND	1	0.67
TRUST TERRITORY	17	11.33

Country of Birth	2008 Frequency	2008 Percent
UGANDA	1	0.67
UNITED STATES	27	18.00
VENEZUELA	1	0.67
VIETNAM	2	1.33

Table 3. Ten Year Cumulative Summary of U.S. HD Cases by Birth Country

Country of Birth	10 Year Cumulative Frequency	10 Year Cumulative Percent
Missing	12	0.79
ALBANIA	1	0.07
AMERICAN SAMOA	13	0.86
ARGENTINA	1	0.07
BAHAMAS	1	0.07
BANGLADESH	4	0.26
BOLIVIA	1	0.07
BRAZIL	111	7.31
BURMA	9	0.59
BURUNDI	1	0.07
CAPE VERDE	3	0.20
CHILE	1	0.07
CHINA	9	0.59
COLOMBIA	14	0.92
CONGO	1	0.07
COSTA RICA	3	0.20
CUBA	43	2.83
DOMINICAN REPUBLIC	45	2.96
ECUADOR	8	0.53
EGYPT	2	0.13
EL SALVADOR	3	0.20
ENGLAND	1	0.07
ETHIOPIA	5	0.33
FIJI	1	0.07
GAMBIA	1	0.07
GUAM	2	0.13
GUATEMALA	3	0.20
GUYANA	16	1.05

Country of Birth	10 Year Cumulative Frequency	10 Year Cumulative Percent
HAITI	9	0.59
INDIA	110	7.24
INDONESIA	11	0.72
IRAN	1	0.07
ITALY	1	0.07
IVORY COAST	2	0.13
JAMAICA	3	0.20
JAPAN	1	0.07
JORDAN	1	0.07
KAMPUCHEA	6	0.39
KENYA	2	0.13
KOREA	1	0.07
LAOS	8	0.53
LEBANON	2	0.13
LIBERIA	4	0.26
MALAYSIA	1	0.07
MEXICO	248	16.33
MICRONESIA	67	4.41
NEW ZEALAND	1	0.07
NIGERIA	10	0.66
PAKISTAN	10	0.66
PAPUA NEW GUINEA	1	0.07
PARAGUAY	3	0.20
PHILIPPINES	128	8.43
POLAND	1	0.07
PUERTO RICO	33	2.17
SENEGAL	1	0.07
SOLOMON ISLANDS	1	0.07
SOMALIA	5	0.33
SRI LANKA	2	0.13

Country of Birth	10 Year Cumulative Frequency	10 Year Cumulative Percent
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	10	0.66
TRUST TERRITORY	65	4.28
UGANDA	1	0.07
UNITED STATES	336	22.12
UNKNOWN	60	3.95
VENEZUELA	2	0.13
VIETNAM	36	2.37
VIRGIN ISLANDS	2	0.13
WESTERN SAMOA	3	0.20

Figure 4. U.S. HD Cases by Reported Ethnicity

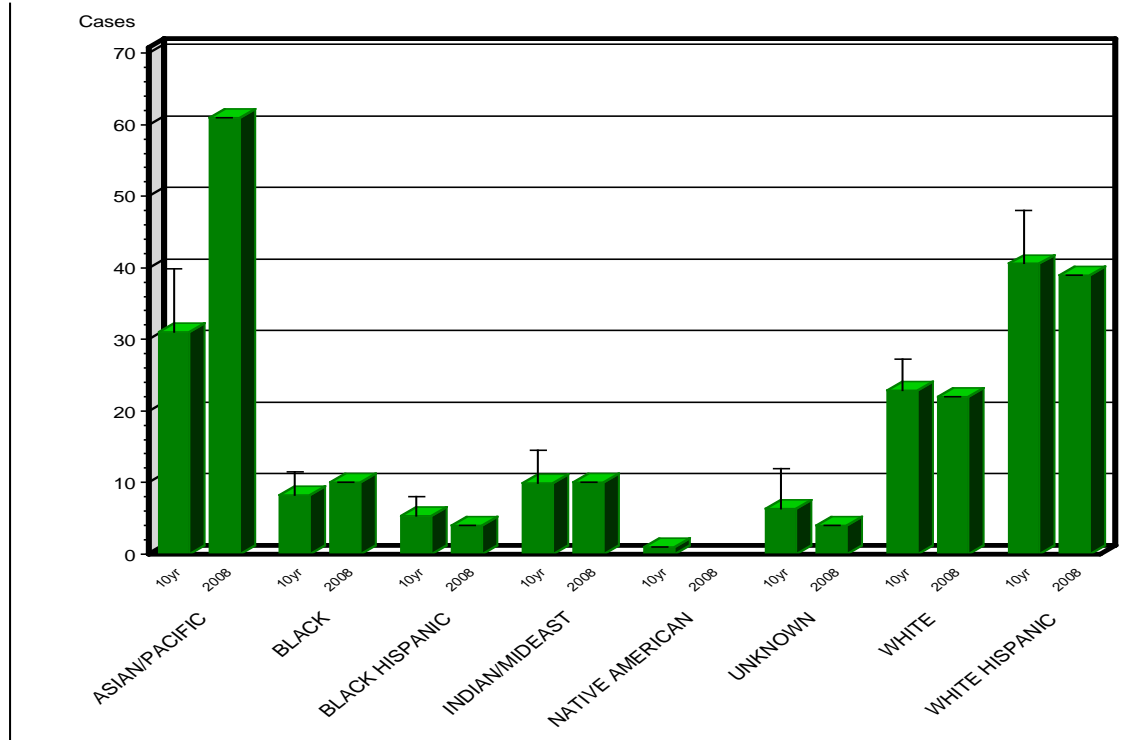


Table 4. 2008 and Ten Year Cumulative Summary of U.S. HD Cases by Ethnicity

Ethnicity	2008 Frequency	2008 Percent	10 year Cumulative Frequency	10 year Cumulative Percent
Missing	0	0	12	0.79
AMERICAN INDN OR ALASKA NAT	0	0	4	0.26
ASIAN OR PACIFIC ISLANDER	61	40.67	412	27.12
BLACK, NOT OF HISPANIC ORIGIN	10	6.67	99	6.52
HISPANIC, BLACK	4	2.67	55	3.62
HISPANIC, WHITE	39	26.00	479	31.53
INDIAN, MIDDLE EASTERNER	10	6.67	99	6.52
NOT SPECIFIED/DECLARED	4	2.67	88	5.79
WHITE, NOT OF HISPANIC ORIGIN	22	14.67	271	17.84

Table 5. 2008 and 10 Year Summary of U.S. HD Case Classification

a) Diagnosis Code

Diagnosis Code	2008 Frequency	2008 Percent	10 Year Cumulative Frequency	10 Year Cumulative Percent
Missing	0	0	5	0.33
030.0	105	70.00	795	52.34
030.1	27	18.00	379	24.95
030.2	5	3.33	58	3.82
030.3	10	6.67	168	11.06
030.8	0	0	7	0.46
030.9	3	2.00	107	7.04

b) Ridley-Jopling Classification

Ridley-Jopling Classification	2008 Frequency	2008 Percent	10 Year Cumulative Frequency	10 Year Cumulative Percent
Missing	13	8.67	357	23.50
Borderline	6	4.00	95	6.25
Borderline Lepromatous	22	14.67	176	11.59
Borderline Tuberculoid	21	14.00	193	12.71
Indeterminate	5	3.33	61	4.02
Lepromatous Leprosy	74	49.33	511	33.64
Tuberculoid	9	6.00	121	7.97

c) WHO Classification

WHO Classification	2008 Frequency	2008 Percent	10 Year Cumulative Frequency	10 Year Cumulative Percent
Missing	0	0	642	42.26
MULTIBACILLARY	106	70.67	550	36.21
PAUCIBACILLARY	44	29.33	327	21.53

Figure 5a. 2008 U.S. HD Cases by Classification

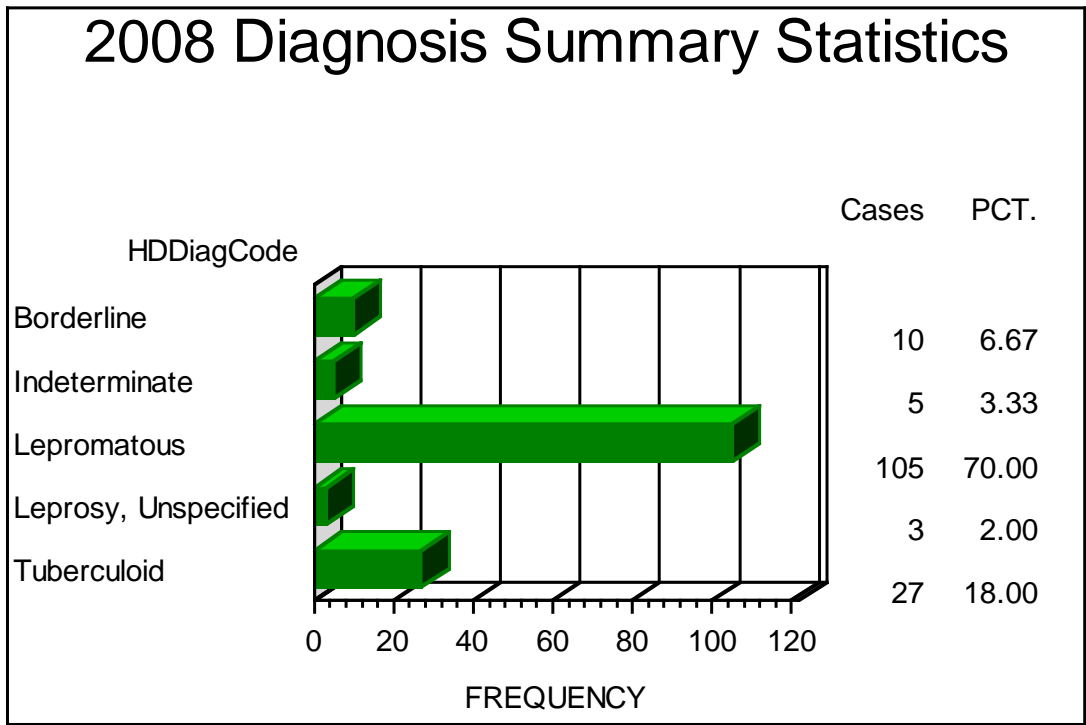


Figure 5b. Ten Year Cumulative Summary of U.S. HD cases by Classification

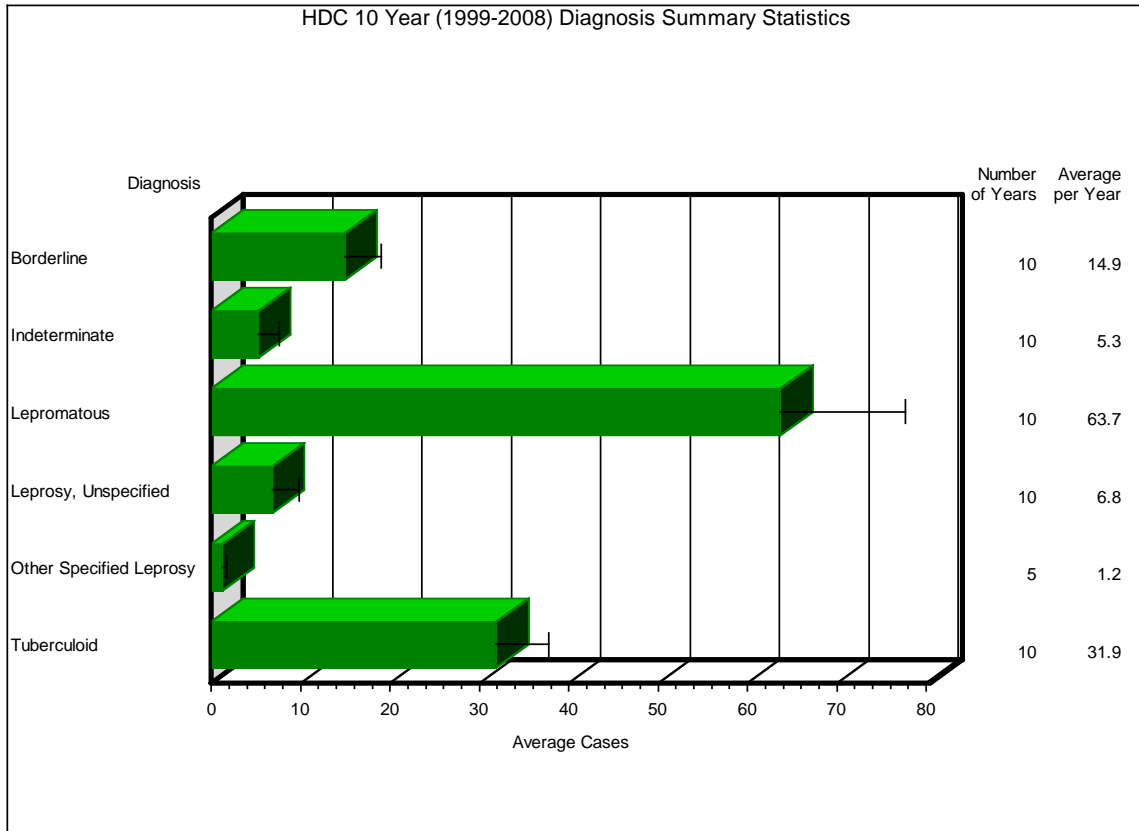


Figure 6. Gender of U.S. HD Cases in 2008 and last 10 Years

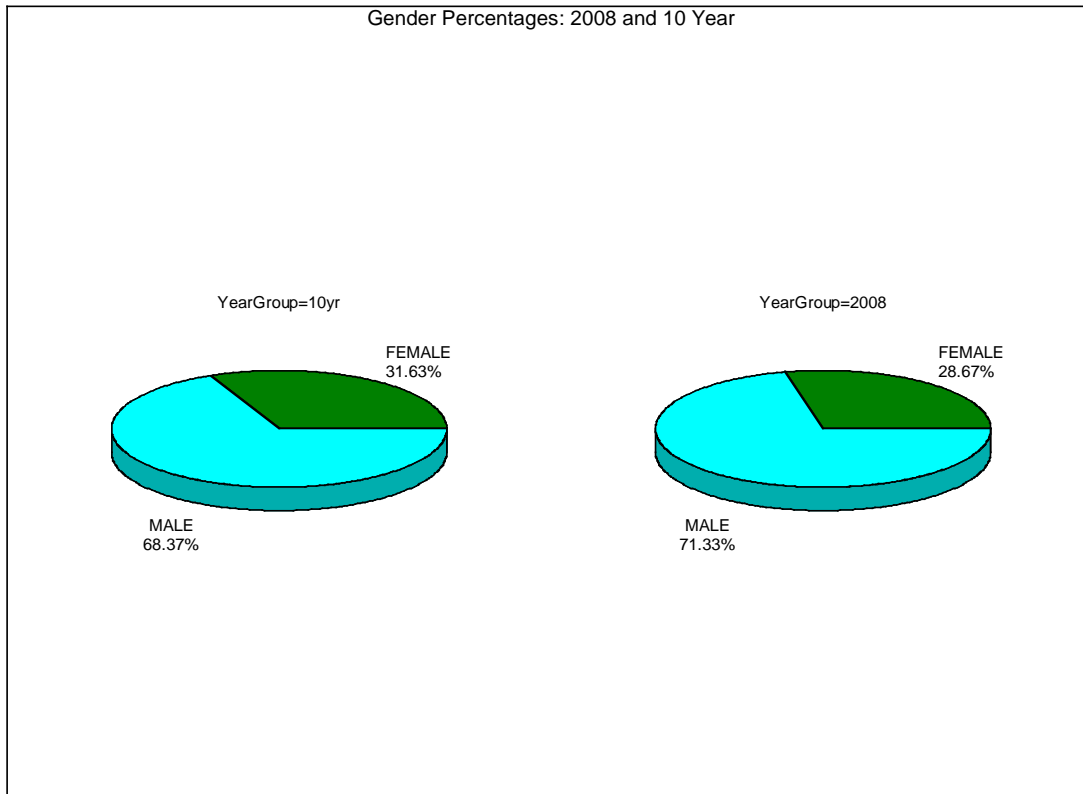


Table 6. 2008 and Ten Year Cumulative Summary of U.S. HD Cases by Gender

Gender	2008 Frequency	2008 Percent	10 year Cumulative Frequency	10 year Cumulative Percent
Missing	0	0	1	0.07
FEMALE	43	28.67	478	31.47
MALE	107	71.33	1040	68.47

Table 7. 2008 and Ten Year Cumulative Summary of U.S. HD Cases by Age

Age Group	2008 Frequency	2008 Percent	10 Year Cumulative Frequency	10 Year Cumulative Percent
Missing	0	0	1	0.07
<16	8	5.33	48	3.16
16 to 30	47	31.33	362	23.83
31 to 45	35	23.33	414	27.25
>45	60	40.00	694	45.69

Table 8a. 2008 U.S. HD Cases by Age and Gender Distribution

2008			
Table of Age Group by Gender			
Age Group	Gender		Total
Frequency Percent	FEMALE	MALE	
<16	4 2.67	4 2.67	8 5.33
16 to 30	9 6.00	38 25.33	47 31.33
31 to 45	9 6.00	26 17.33	35 23.33
>45	21 14.00	39 26.00	60 40.00
Total	43 28.67	107 71.33	150 100.00

Table 8b. Ten Year Cumulative Summary of Distribution of U.S. HD Cases by Age and Gender

10 Year Cumulative Table of Age Group by Gender				
Age Group	Gender			Total
Frequency Percent		FEMALE	MALE	
Missing	1 0.07	0 0.00	0 0.00	1 0.07
<16	0 0.00	22 1.45	26 1.71	48 3.16
16 to 30	0 0.00	105 6.91	257 16.92	362 23.83
31 to 45	0 0.00	121 7.97	293 19.29	414 27.25
>45	0 0.00	230 15.14	464 30.55	694 45.69
Total	1 0.07	478 31.47	1040 68.47	1519 100.0

Figure 7. 2008 and Ten Year Cumulative Summary of U.S. HD Cases by Age

