A Summary of Hansen's Disease in the United States-2007

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

Introduction

The mission of the 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 healthcare 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 1980 (median year). The total number of U.S. cases registered by the end of 2007 was 12,322. The following is a general demographic summary of the cases reporting in 2007.

Table of Contents:

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 Prevalance 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 157 cases were newly reported to the National Hansen's Disease Registry (NHDR) in 2007. While this number is a 13 percent increase from 2006, it 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 12322 Hansen's Disease cases have been registered in the United States since 1894. Based on estimates of life expectancy, some 6883 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 32 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 2007, and collectively accounted for 58 percent (91/157) of the cases registered. The predominance of these States is in keeping with the ten 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 2007, a total of eight cases were reported from Hawaii, and six from Puerto Rico. Reporting from Hawaii generally exceeds the historical trend for the state and reflects enhanced reporting from that state.

A total of 33 cases were reported from Texas (23) and Louisiana (10). The combined number of cases is consistent with the historical norms from these States. About half (15/33) 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 1700's and its relationship to transmission from the armadillo zoonotic reservoir is a topic of current investigation.

National Origin

Of the 157 reported cases, 128 (81 percent) recorded a location other than the United States as their place of birth. Collectively, national origin of the cases reported in 2007 could be associated with a total of 26 different countries or territories (Table 2). Of the 26 different birth countries reported, more than half of the cases reporting (72) presented from Brazil (26), India (18), Mexico (17), and the Philippines (11). Another 19 cases arose from among the Trust Territories (12), Micronesia (7) or American or Western Samoa (4) reflecting a continuing high rate of disease in these populations that has began to emerge in the late 1960's 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 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 2007 the WHO reported that only 259,017 new cases were

registered worldwide, representing a greater than 60 percent decline in annual new case numbers registered since 2001. Unfortunately, nearly all of this reduction has been observed 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 2007, the largest number of our cases (53/157, 34 percent) identify themselves as being whites of Hispanic origin. The next leading group was Asian or Pacific Islanders. The largest proportion of cases (82/157) that identified an ethnic association in 2007 declared themselves to be Whites.

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 2007 is shown in Table 5 and depicted graphically in Figures 5a and 5b. The majority (130/157, 82 percent) of U.S. cases are coded as either 030.0 or 030.1 and correspond to either lepromatous (53 percent) or tuberculoid (29 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. Consistent with the diagnosis code data the majority (59/136) of U.S. cases are classified a lepromatous, but a roughly equivalent number (56/136) express borderline forms of the disease.

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 ten 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 157 cases reported to the registry in 2007, 72 percent (114/157) were male and 27 percent (43/157) 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 7 to 80 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.

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Figure 1. U.S. Reported Hansen's Disease Cases by Year

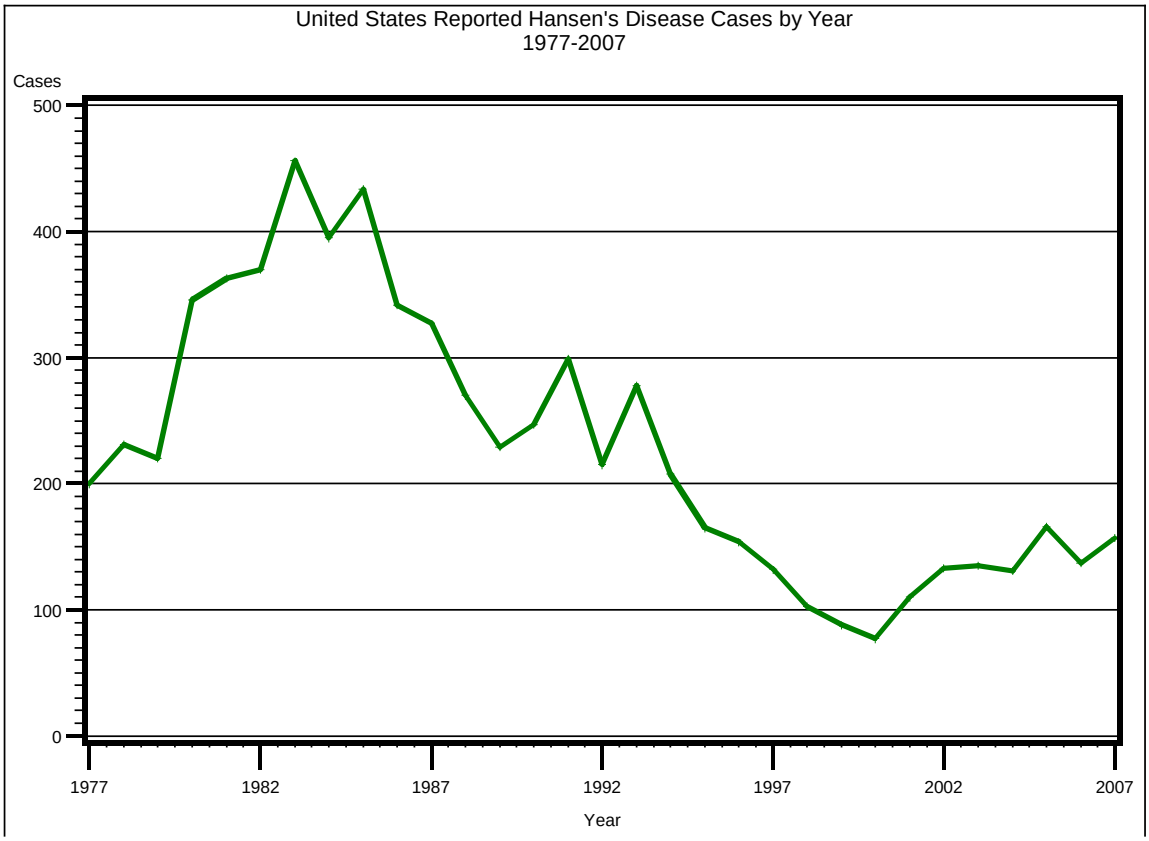

Table 1a. 2007 Summary of Hansen's Disease Cases by State Reporting

State Reporting	2007 Frequency	2007 Percent
ALABAMA	1	0.64
ALASKA	2	1.27
ARIZONA	1	0.64
ARKANSAS	5	3.18
CALIFORNIA	17	10.83
CONNECTICUT	3	1.91
FLORIDA	19	12.10
GEORGIA	3	1.91
HAWAII	8	5.10
IDAHO	2	1.27
IOWA	4	2.55
KANSAS	1	0.64
LOUISIANA	10	6.37
MARYLAND	1	0.64
MASSACHUSETTS	10	6.37
MICHIGAN	2	1.27
MINNESOTA	3	1.91
MISSISSIPPI	1	0.64
MISSOURI	2	1.27
NEVADA	1	0.64
NEW JERSEY	2	1.27
NEW MEXICO	1	0.64
NEW YORK	14	8.92
OHIO	1	0.64
OREGON	5	3.18
PENNSYLVANIA	3	1.91
PUERTO RICO	6	3.82
SOUTH CAROLINA	2	1.27

State Reporting	2007 Frequency	2007 Percent
TEXAS	23	14.65
VIRGINIA	1	0.64
WASHINGTON	2	1.27
WISCONSIN	1	0.64

Table 1b. Ten Year Summary of Hansen's Disease Cases by Reporting State

State Reporting	10 Year Cumulative Frequency	10 Year Cumulative Percent
Missing .	18	1.31
ALABAMA	4	0.29
ALASKA	2	0.15
ARIZONA	9	0.66
ARKANSAS	24	1.75
CALIFORNIA	250	18.26
COLORADO	8	0.58
CONNECTICUT	11	0.80
DELAWARE	1	0.07
DISTRICT OF COLUMBIA	1	0.07
FLORIDA	91	6.65
GEORGIA	18	1.31
HAWAII	92	6.72
IDAHO	5	0.37
ILLINOIS	18	1.31
INDIANA	4	0.29
IOWA	14	1.02
KANSAS	2	0.15
KENTUCKY	4	0.29
LOUISIANA	116	8.47
MAINE	1	0.07
MARYLAND	4	0.29
MASSACHUSETTS	52	3.80
MICHIGAN	7	0.51
MINNESOTA	9	0.66
MISSISSIPPI	7	0.51
MISSOURI	6	0.44
NEBRASKA	5	0.37

State Reporting	10 Year Cumulative Frequency	10 Year Cumulative Percent
NEVADA	5	0.37
NEW HAMPSHIRE	1	0.07
NEW JERSEY	11	0.80
NEW MEXICO	2	0.15
NEW YORK	144	10.52
NORTH CAROLINA	4	0.29
OHIO	9	0.66
OKLAHOMA	4	0.29
OREGON	25	1.83
PENNSYLVANIA	25	1.83
PUERTO RICO	47	3.43
RHODE ISLAND	2	0.15
SOUTH CAROLINA	3	0.22
SOUTH DAKOTA	3	0.22
TENNESSEE	7	0.51
TEXAS	233	17.02
UTAH	6	0.44
VIRGINIA	8	0.58
WASHINGTON	42	3.07
WEST VIRGINIA	1	0.07
WISCONSIN	4	0.29

Figure 2. 2007 U.S. Hansen's Disease Cases by State

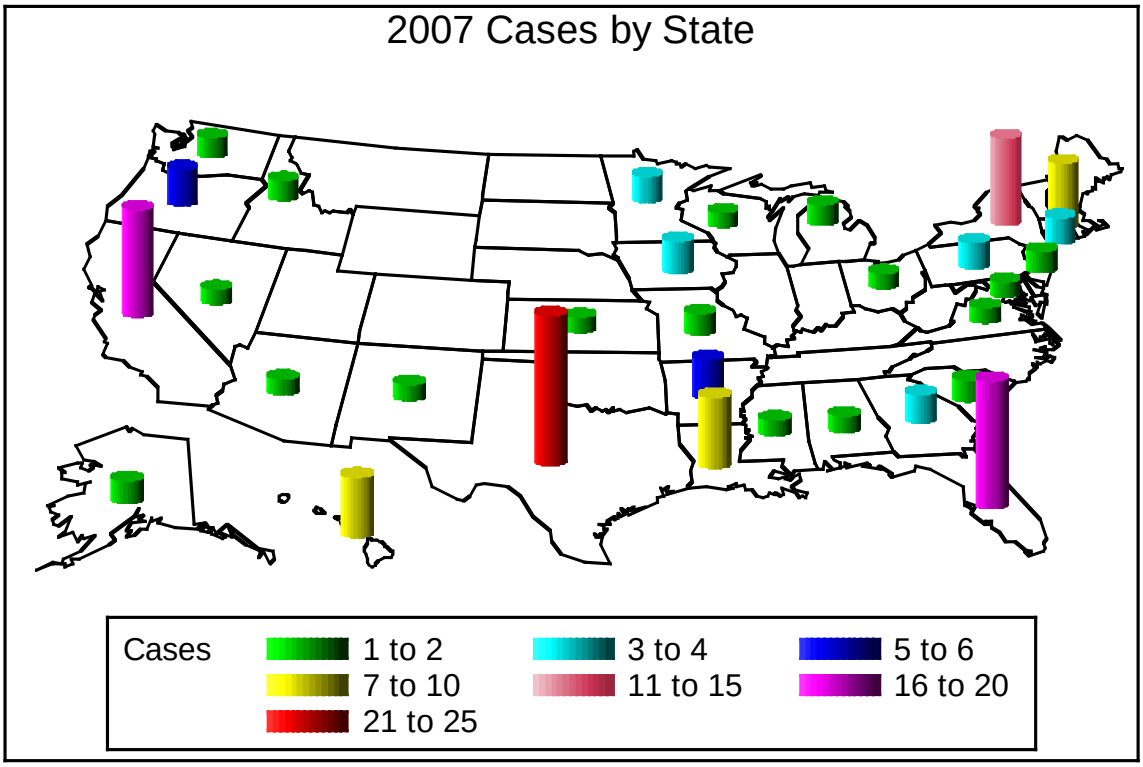

Figure 3. 10 Year Average U.S. Hansen's Disease Cases by State

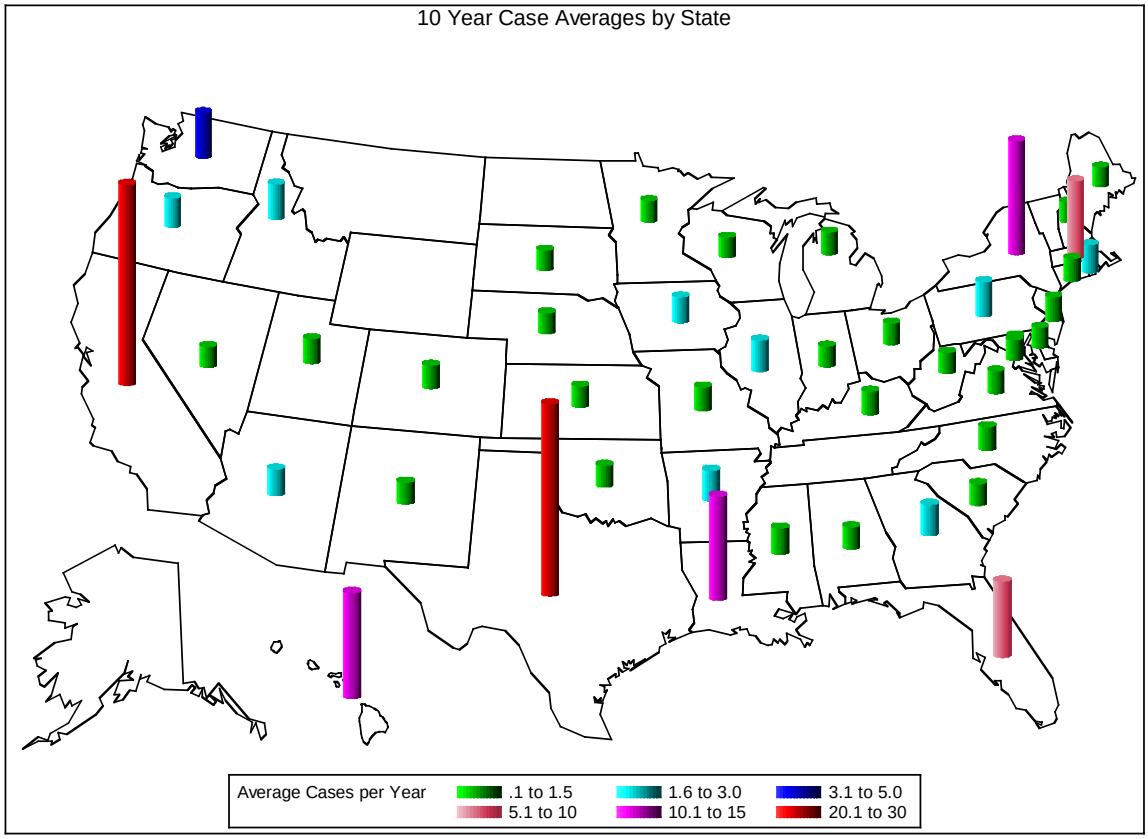

Table 2. 2007 U.S. Hansen's Disease cases by Birth Country

Country of Birth	2007 Frequency	2007 Percent
AMERICAN SAMOA	4	2.55
BOLIVIA	1	0.64
BRAZIL	26	16.56
BURMA	2	1.27
BURUNDI	1	0.64
COLOMBIA	4	2.55
CUBA	7	4.46
DOMINICAN REPUBLIC	1	0.64
EL SALVADOR	1	0.64
GUYANA	2	1.27
INDIA	18	11.46
JAMAICA	1	0.64
KOREA	1	0.64
MEXICO	17	10.83
MICRONESIA	7	4.46
PAKISTAN	1	0.64
PHILIPPINES	11	7.01
POLAND	1	0.64
PUERTO RICO	7	4.46
SUDAN	1	0.64
TANZANIA	1	0.64
TRUST TERRITORY	12	7.64
UNITED STATES	29	18.47
VIETNAM	1	0.64

Table 3. Ten Year Summary of U.S. Hansen's Disease Cases by Birth Country

Country of Birth	10 Year Cumulative Frequency	10 Year Cumulative Percent
Missing .	12	0.88
ALBANIA	1	0.07
AMERICAN SAMOA	12	0.88
ARGENTINA	1	0.07
BAHAMAS	1	0.07
BANGLADESH	4	0.29
BOLIVIA	1	0.07
BRAZIL	96	7.01
BURMA	7	0.51
BURUNDI	1	0.07
CAPE VERDE	2	0.15
CHILE	1	0.07
CHINA	8	0.58
COLOMBIA	13	0.95
CONGO	1	0.07
COSTA RICA	3	0.22
CUBA	41	2.99
DOMINICAN REPUBLIC	41	2.99
ECUADOR	7	0.51
EGYPT	1	0.07
EL SALVADOR	3	0.22
ETHIOPIA	2	0.15
FIJI	1	0.07
GAMBIA	1	0.07
GUATEMALA	2	0.15
GUYANA	14	1.02
HAITI	8	0.58
INDIA	100	7.30

Country of Birth	10 Year Cumulative Frequency	10 Year Cumulative Percent
INDONESIA	11	0.80
IRAN	1	0.07
IVORY COAST	1	0.07
JAMAICA	3	0.22
JAPAN	1	0.07
JORDAN	1	0.07
KAMPUCHEA	6	0.44
KENYA	2	0.15
KOREA	1	0.07
LAOS	8	0.58
LEBANON	1	0.07
LIBERIA	4	0.29
MALAYSIA	1	0.07
MEXICO	229	16.73
MICRONESIA	55	4.02
NEW ZEALAND	1	0.07
NIGERIA	10	0.73
PAKISTAN	9	0.66
PAPUA NEW GUINEA	1	0.07
PARAGUAY	2	0.15
PHILIPPINES	113	8.25
POLAND	1	0.07
PUERTO RICO	33	2.41
SENEGAL	1	0.07
SOLOMON ISLANDS	1	0.07
SOMALIA	5	0.37
SRI LANKA	2	0.15
ST CHRISTOPHER NEVIS ST KITTS	1	0.07
SUDAN	7	0.51
SURINAME	2	0.15

Country of Birth	10 Year Cumulative Frequency	10 Year Cumulative Percent
TAIWAN	1	0.07
TANZANIA	1	0.07
THAILAND	1	0.07
TRINIDAD AND TOBAGO	10	0.73
TRUST TERRITORY	48	3.51
UNITED STATES	309	22.57
UNKNOWN	60	4.38
VENEZUELA	1	0.07
VIETNAM	34	2.48
VIRGIN ISLANDS	2	0.15
WESTERN SAMOA	3	0.22

Figure 4. U.S. Hansen's Disease Cases by Ethnicity

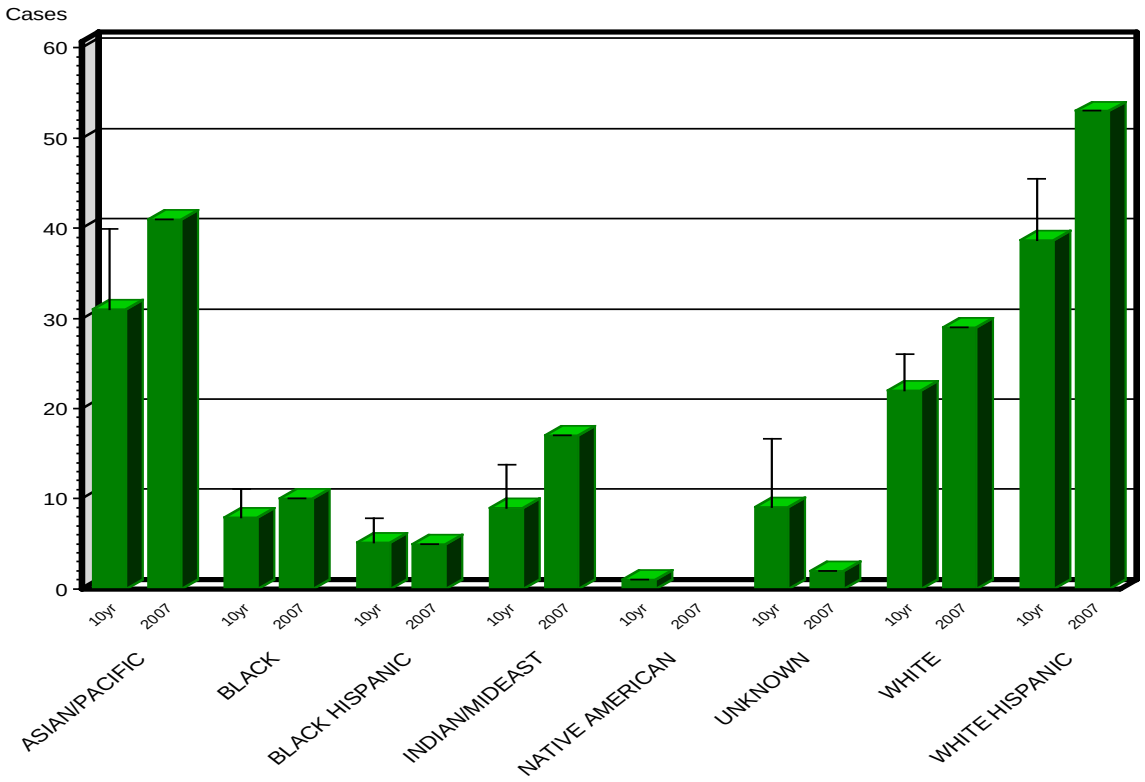

Table 4. 2007 & 10 Year Cumulative U.S. Hansen's Disease Cases by Ethnicity

Reported Ethnicity	2007 Frequency	2007 Percent	10 Year Cumulative Frequency	10 Year Cumulative Percent
ASIAN OR PACIFIC ISLANDER	41	26.11	351	25.64
BLACK, NOT OF HISPANIC ORIGIN	10	6.37	89	6.5
HISPANIC, BLACK	5	3.18	51	3.73
HISPANIC, WHITE	53	33.76	440	32.14
INDIAN, MIDDLE EASTERNER	17	10.83	89	6.50
NOT SPECIFIED/UNKNOWN	2	1.27	84	6.14
WHITE, NOT OF HISPANIC ORIGIN	29	18.47	249	18.19

Table 5. 2007 and 10 Year Summary of U.S. Hansen's Disease Cases by :

a) Diagnosis Code

HD Diagnosis Code	2007 Frequency	2007 Percent	10 Year Cumulative Frequency	10 Year Cumulative Percent
Missing .	0	0	5	0.37
030.0	84	53.50	690	50.40
030.1	46	29.30	352	25.71
030.2	11	7.01	53	3.87
030.3	10	6.37	158	11.54
030.8	1	0.64	7	0.51
030.9	5	3.18	104	7.60

b) Ridley-Jopling Classification

Ridley-Jopling HD Classification	2007 Frequency	2007 Percent	10 Year Cumulative Frequency	10 Year Cumulative Percent
Missing .	21	13.38	344	25.13
Borderline	6	3.82	89	6.50
Borderline Lepromatous	14	8.92	154	11.25
Borderline Tuberculoid	36	22.93	172	12.56
Indeterminate	12	7.64	56	4.09
Lepromatous Leprosy	59	37.58	437	31.92
Tuberculoid	7	4.46	112	8.18

c) WHO Classification

WHO Classification	2007 Frequency	2007 Percent	10 Year Cumulative Frequency	10 Year Cumulative Percent
Missing .	4	2.55	642	46.90
MULTIBACILLARY	89	56.69	444	32.43
PAUCIBACILLARY	64	40.76	283	20.67

Figure 5a. 2007 U.S. Hansen's Disease Cases by Classification.

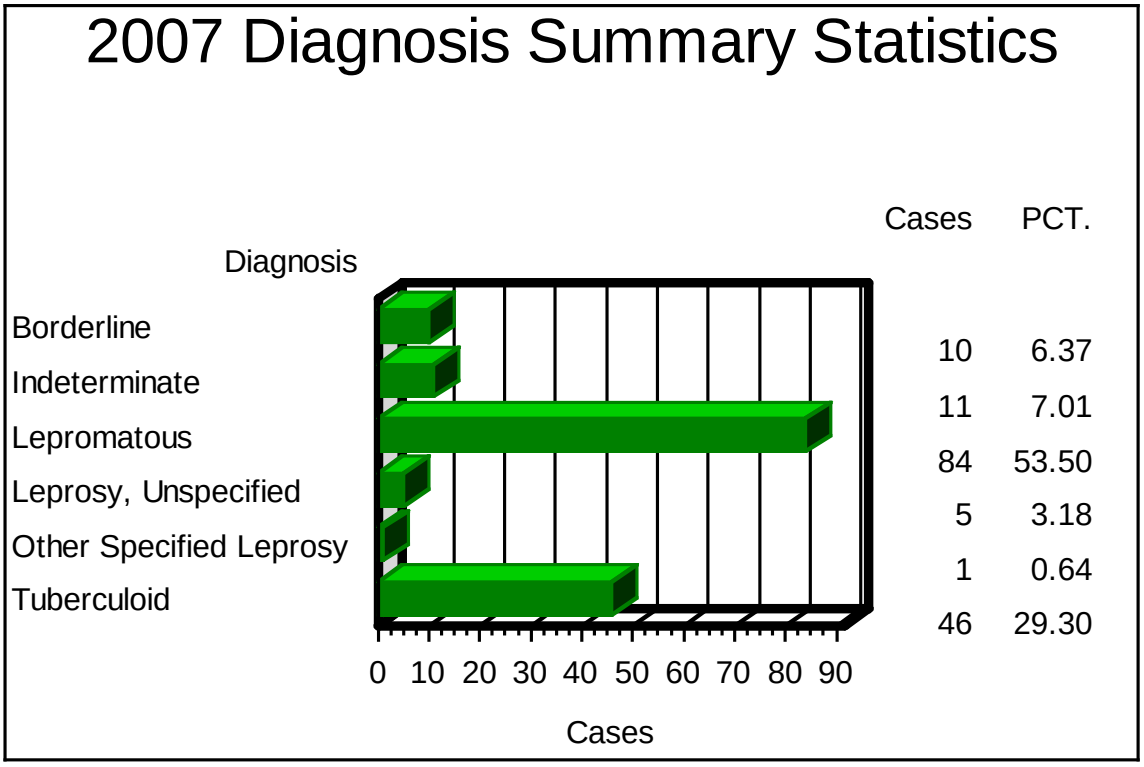

Figure 5b. Ten Year Summary of U.S. Hansen's Disease Cases by Classification.

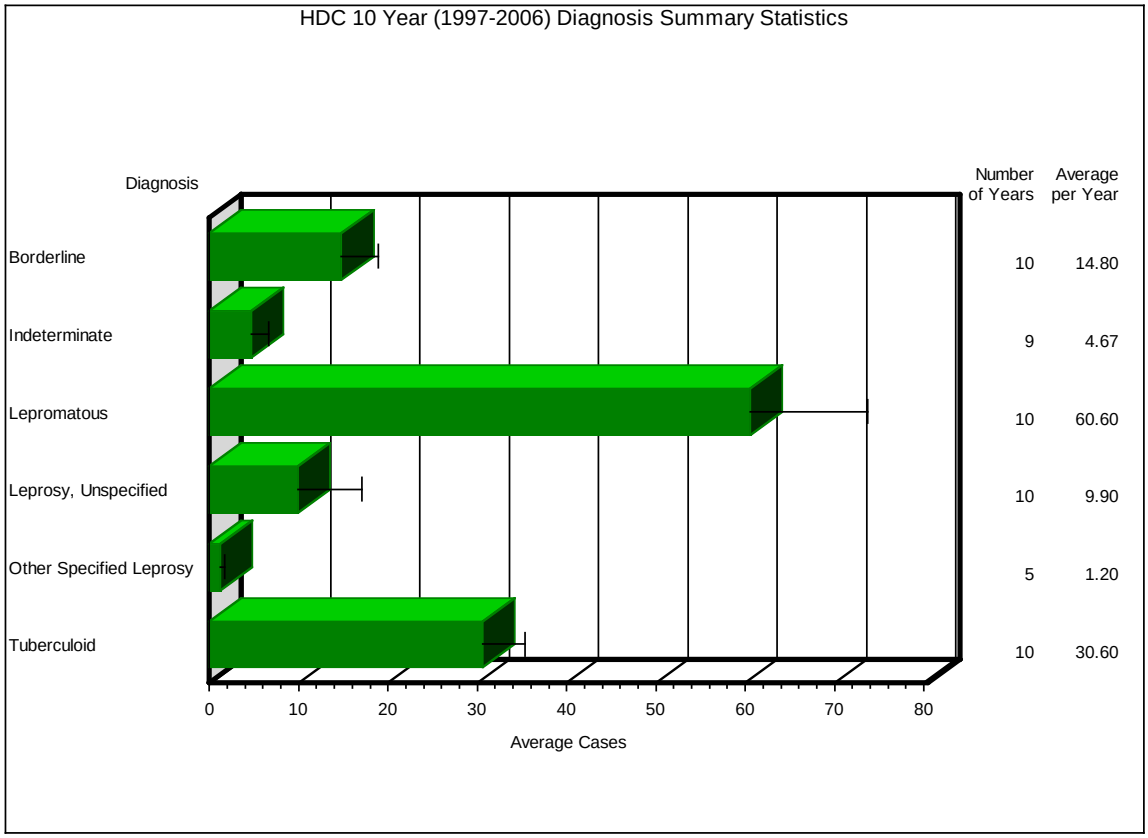

Figure 6. Gender of U.S. Hansen's Disease Cases in 2007 and last 10 years.

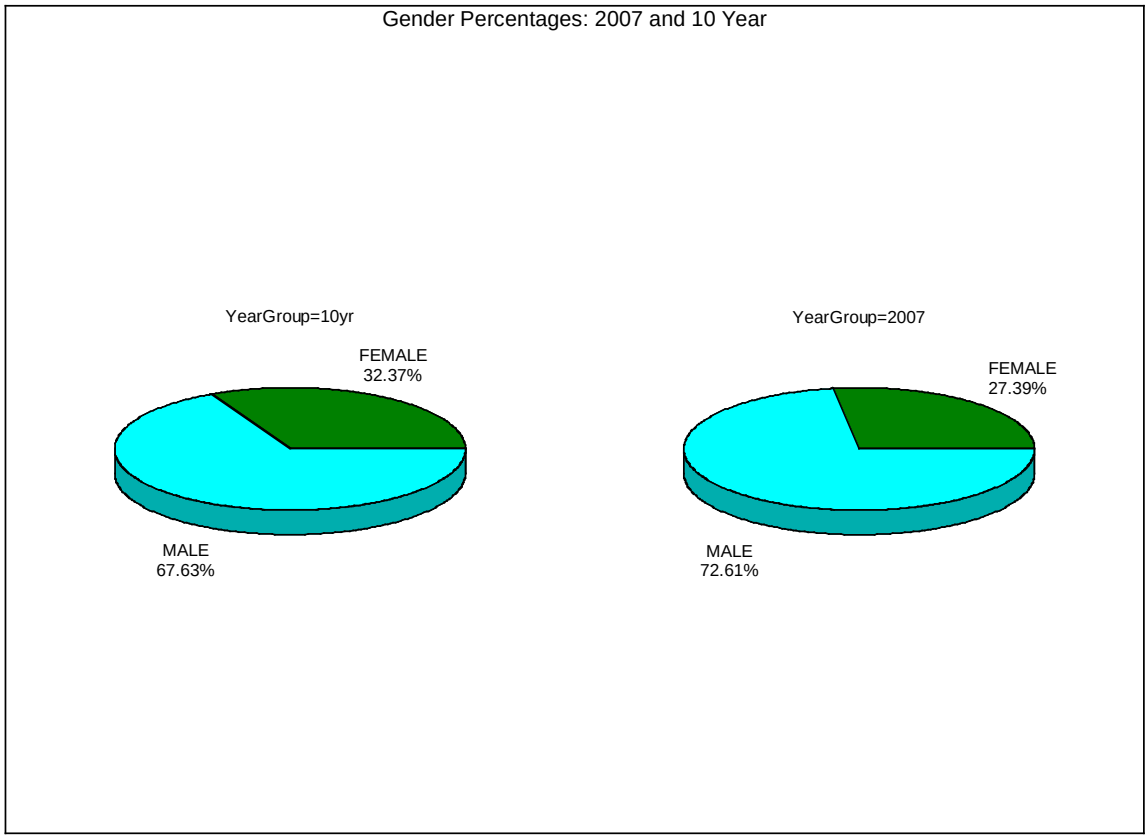

Table 6. 2007 U.S. Hansen's Disease Cases by Gender

Gender	2007 Frequency	2007 Percent	10 Year Cumulative Frequency	10 Year Cumulative Percent
Missing .	0	0	1	0.07
FEMALE	43	27.39	435	31.78
MALE	114	72.61	933	68.15

Table 7. 2007 and 10 Year Summary of U.S. Hansen's Disease Cases by Age

Age Group Years	2007 Frequency	2007 Percent	10 Year Cumulative Frequency	10 Year Cumulative Percent
Missing	0	0	1	0.07
<16	2	1.27	40	2.92
16 to 30	33	21.02	315	23.01
31 to 45	55	35.03	379	27.68
>45	67	42.68	634	46.31

Table 8a. 2007 U.S. Hansen's Disease Case Age and Gender Distribution

2007 Table of Age Group by Gender			
Age Group	**Gender**		
Frequency **Percent**	**FEMALE**	**MALE**	**Total**
Missing.			
<16	2 1.27	0 0.00	2 1.27
16 to 30	11 7.01	22 14.01	33 21.02
31 to 45	12 7.64	43 27.39	55 35.03
>45	18 11.46	49 31.21	67 42.68
Total	43 27.39	114 72.61	157 100.0

Table 8b. 10 Year Cumulative U.S. Hansen's Disease Case Age and Gender Distribution

10 Year Cumulative Table of Age Group by Gender				
Age Group	**Gender**			
Frequency Percent	**Missing**	**FEMALE**	**MALE**	**Total**
Missing	1 0.07	0 0.00	0 0.00	1 0.07
<16	0 0.00	18 1.31	22 1.61	40 2.92
16 to 30	0 0.00	96 7.01	219 16.00	315 23.01
31 to 45	0 0.00	112 8.18	267 19.50	379 27.68
>45	0 0.00	209 15.27	425 31.04	634 46.31
Total	1 0.07	435 31.78	933 68.15	1369 100.0

Figure 7. 2007 & 10 Year Summary of U.S. Hansen's Disease Cases by Age