



A Summary of Hansen's Disease in the United States-2006

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 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, customized reports 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 2006 was 12,162. The following is a general demographic summary of the cases reporting in 2006.

2006 Registry Summary

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Temporal Distribution and Reporting

A total of 137 cases were reported to the National Hansen's Disease Registry (NHDR) in 2006. While this number represents a 20 percent decline from 2005 it is in keeping with the general trend of 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. Those annual numbers have increased steadily to this point in time and may now have stabilized.

The monthly number of cases registered in 2006 ranged from a low of 1 in December to a high of 25 in January (Figure 2). 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 probably the result of other operational issues. Comparing monthly registration trends over the last 10 years shows that registration reports tend to be returned at a fairly constant rate throughout the year, and there is no substantive intra-year temporal trend for reporting cases to the HD Registry (Figure 3). Inspection of reporting records suggests there may be some confusion among State health departments and local practitioners with regards to the process of reporting HD cases. Some cases are reported to the CDC but not to the NHDP, and others go wholly unreported for several years. We are working with CDC personnel to resolve this issue.

Geographic Distribution

HD cases were reported from 30 U.S. states (including Puerto Rico) in 2006 (Table 1). 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 4 and 5 respectively. California, Florida, Louisiana, Massachusetts, New York and Texas contributed the largest number of cases in 2006, and collectively accounted for 63 percent (86/137) of the cases registered. The predominance of these States is in keeping with the ten year trend in reporting, which also would identify New Jersey, Hawaii, Pennsylvania, Washington and Arkansas 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 2006, a total of nine cases were reported from Hawaii, but only one from Puerto Rico. Reporting from Hawaii generally exceeds the historical trend for the state and was almost exclusively among immigrants from Micronesia or the Trust Territories where HD is highly endemic.

A total of 20 cases were reported from Texas (11) and Louisiana (9). The combined number of cases is consistent with the historical norms from these States, but slightly higher in Louisiana. More than half (13/20) of all these cases were native born U.S. citizens with no residence history outside the United States. Inspection of the Louisiana data also suggests that there is some late reporting of cases that had been diagnosed in earlier years. This may reflect an increasing awareness of disease in the State or an

increasing rate of new infection. The consistency of this trend and the potential long term impact of disruptions caused by recent hurricanes on disease awareness and reporting merits additional consideration.

National Origin

Of the 137 reported cases, 116 (85 percent) recorded a location other than the United States as their place of birth. Collectively, national origin of the cases reported in 2006 could be associated with a total of 26 different countries or territories (Table 2). Of the 26 total birth countries reported, the majority of cases (68 percent) presented from the Philippines (22), United States (21), Mexico (20), Brazil (4), and India (9) respectively. Another 23 cases arose from among the Trust Territories (11), Micronesia (5) or American or Western Samoa (1), or Viet Nam (6) . 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 cured. In 2006 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 2006 is shown in Figure 6. The 2006 distribution was in keeping with the 10 year trend and shows a broad involvement of ethnic groups. In 2006, the largest number of our cases (49/137, 36 percent) identify themselves as being of Asian/Pacific origin, followed closely by Hispanic Whites and Blacks (48/137, 35 percent). The largest proportion of cases (61/137) that identified an ethnic association declared themselves to be Whites in 2006.

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 classification is completed more consistently than other disease classification methods on the HD Surveillance Form in the United States. The diagnosis code distribution of classifications registered in 2006 is shown in Table 4a. The majority (107/137, 78 percent) of U.S. cases are coded as either 030.0 or 030.1 and correspond to either lepromatous (50 percent) or tuberculoid (27 percent) disease respectively. Comparing these percentages to the 10 year trend of reported codes (Table 4b) shows no significant variation, and these 2006 reports 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 2006, and their 10 year trends, are shown in Tables 5a and 5b respectively. Consistent with the diagnosis code data the majority (44/113) of U.S. cases are classified a lepromatous, but a roughly equivalent number (50/113) 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 and Lepromatous classes from the ICM-9 codes. Likewise, Paucibacillary cases can be identified by grouping the remaining categories. For 2006, 72 (53 percent) of the reported cases are grouped as Multibacillary and 62 (45 percent) as Paucibacillary according to this classification scheme (Tables 6a). These data are in keeping with the ten year trend of reporting as summarized in Table 6b, and illustrated graphically for 2006 in Figure 7 and for the preceding 10 year period in Figure 8.

Age and Gender

Of the 137 cases reported to the registry in 2006, 67 percent (92/137) were male and 33 percent (45/137) were female (Table 7a). These data are in keeping with long term trends in the gender distribution of U.S. cases (Table 7b). 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 9).

The age distribution of U.S. cases in 2006 is summarized in Table 8a and over the last 10 years in Table 8b. Further demographic breakdown of cases by age and gender is shown in the sub-part of each table. In 2006, the age of all registrants ranged from 7 to 83 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
Rtruman@HRSA.gov.*

National Hansen's Disease Programs
1770 Physician's Park Drive
Baton Rouge, Louisiana 70816
800-642-2477

Appendices:

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

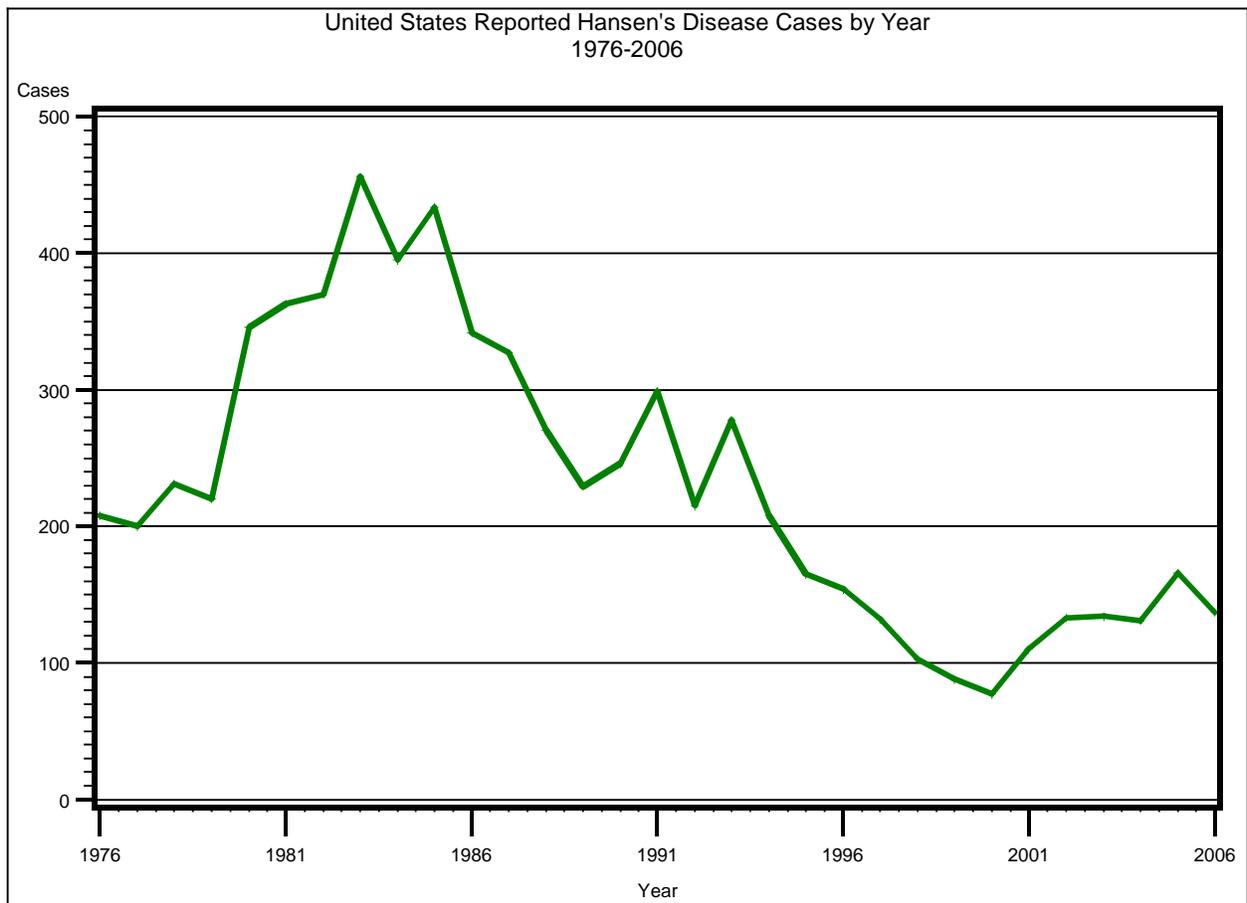


Figure 2. U.S. Reported Hansen's Disease Cases by Month in 2006

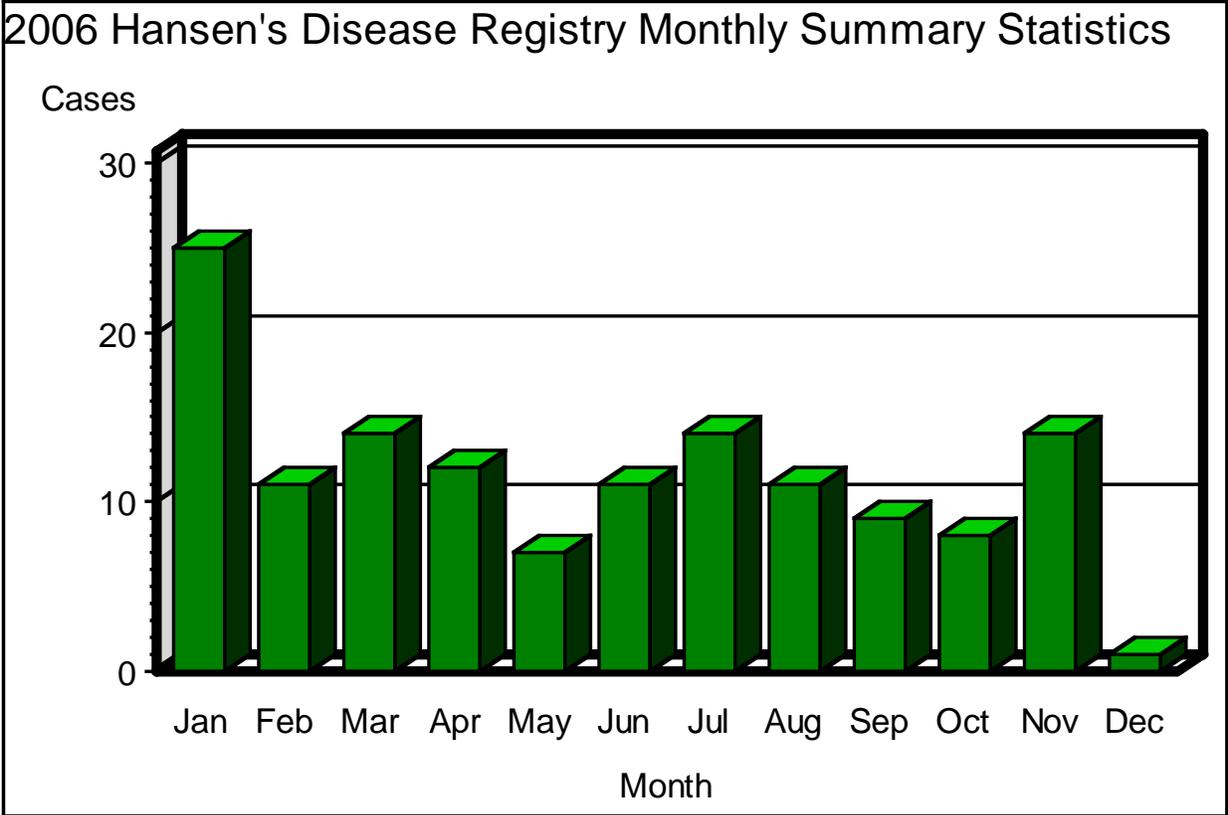


Figure 3. Ten Year U.S. Reported Hansen's Disease Cases by Month

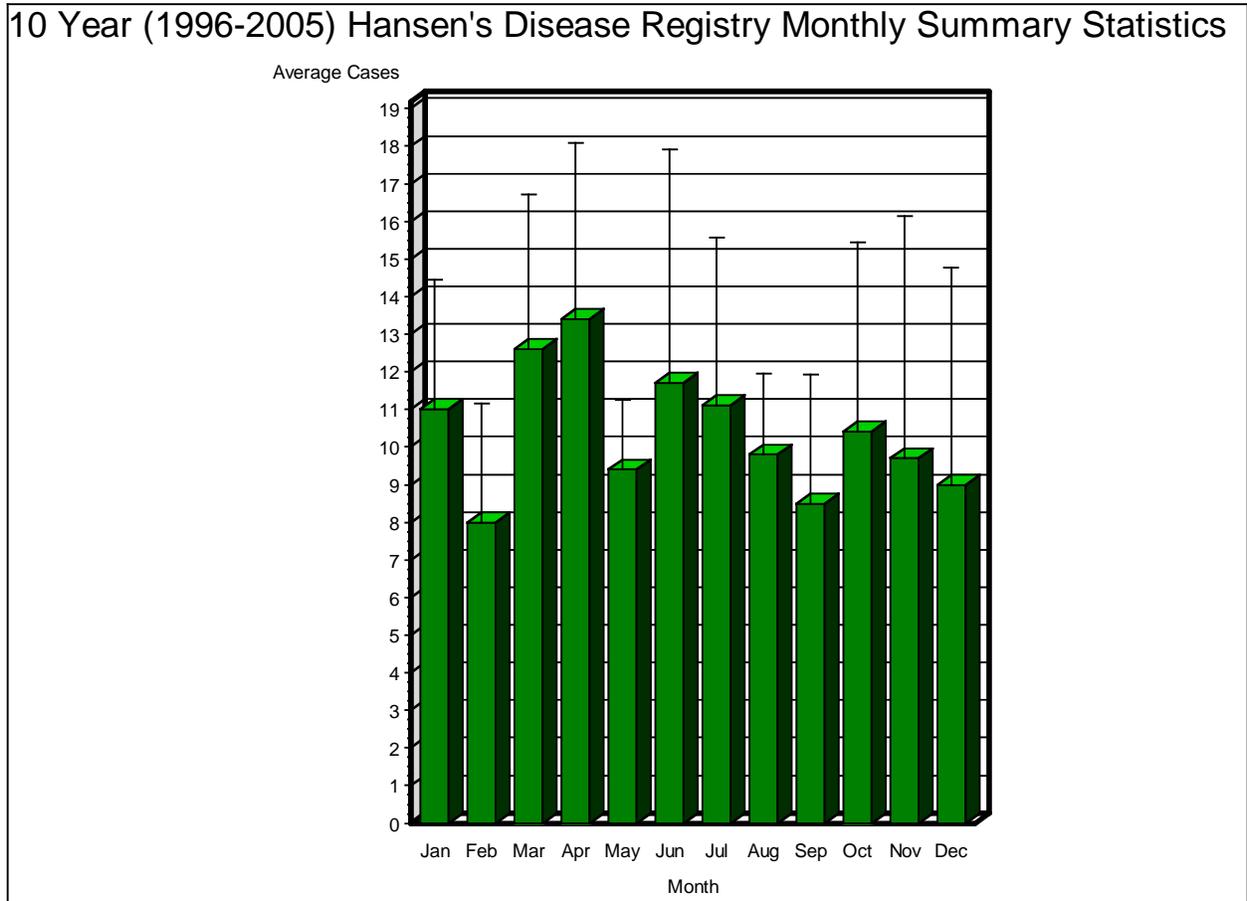


Table 1a: Reporting by U.S. State or Location in 2006

Reporting State	Frequency	Percent
ARIZONA	2	1.46
ARKANSAS	1	0.73
CALIFORNIA	29	21.17
COLORADO	2	1.46
CONNECTICUT	2	1.46
DELAWARE	1	0.73
FLORIDA	16	11.68
GEORGIA	1	0.73
HAWAII	9	6.57
ILLINOIS	6	4.38
IOWA	1	0.73
KENTUCKY	2	1.46
LOUISIANA	10	7.30
MASSACHUSETTS	10	7.30
MINNESOTA	1	0.73
MISSOURI	2	1.46
NEVADA	1	0.73
NEW JERSEY	2	1.46
NEW YORK	10	7.30
NORTH CAROLINA	1	0.73
OHIO	1	0.73
OKLAHOMA	1	0.73
OREGON	2	1.46
PENNSYLVANIA	2	1.46
PUERTO RICO	1	0.73
TEXAS	11	8.03
UTAH	2	1.46
VIRGINIA	1	0.73
WASHINGTON	6	4.38
WISCONSIN	1	0.73

Table 1b: Ten year Trend Summary of State Reporting

Reporting State	Frequency	Percent
(Missing)	73	5.94
ALABAMA	2	0.16
ARIZONA	7	0.57
ARKANSAS	20	1.63
CALIFORNIA	230	18.73
COLORADO	7	0.57
CONNECTICUT	7	0.57
DELAWARE	1	0.08
FLORIDA	71	5.78
FOREIGN COUNTRY	31	2.52
GEORGIA	18	1.47
HAWAII	52	4.23
IDAHO	4	0.33
ILLINOIS	16	1.30
INDIANA	4	0.33
IOWA	9	0.73
KANSAS	1	0.08
KENTUCKY	2	0.16
LOUISIANA	100	8.14
MAINE	1	0.08
MARYLAND	2	0.16
MASSACHUSETTS	37	3.01
MICHIGAN	5	0.41
MINNESOTA	8	0.65
MISSISSIPPI	8	0.65
MISSOURI	4	0.33
NEBRASKA	5	0.41
NEVADA	6	0.49
NEW HAMPSHIRE	2	0.16

Reporting State	Frequency	Percent
NEW JERSEY	32	2.61
NEW MEXICO	1	0.08
NEW YORK	103	8.39
NORTH CAROLINA	3	0.24
NORTH DAKOTA	1	0.08
OHIO	7	0.57
OKLAHOMA	4	0.33
OREGON	19	1.55
PENNSYLVANIA	20	1.63
PUERTO RICO	11	0.90
RHODE ISLAND	3	0.24
SOUTH CAROLINA	1	0.08
SOUTH DAKOTA	2	0.16
TENNESSEE	5	0.41
TEXAS	229	18.65
UTAH	5	0.41
VIRGINIA	10	0.81
WASHINGTON	37	3.01
WISCONSIN	2	0.16

Figure 4. 2006 U.S. Hansen's Disease Cases by State

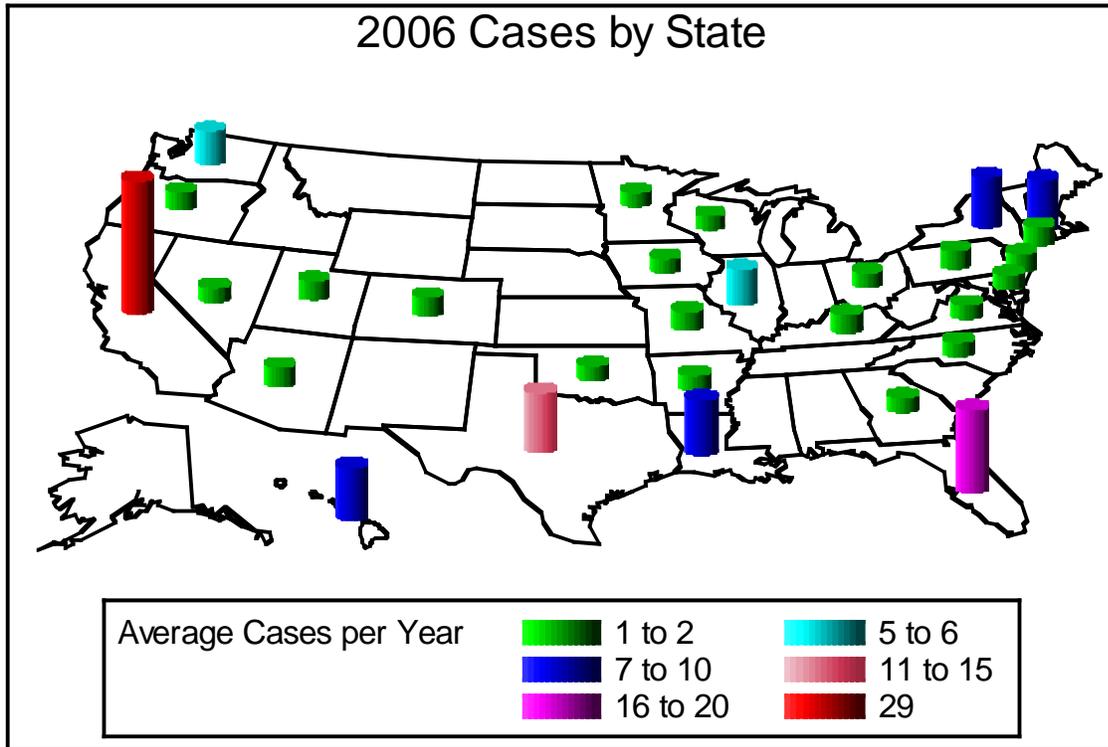


Figure 5. 10 Year Average U.S. Hansen's Disease Cases by State

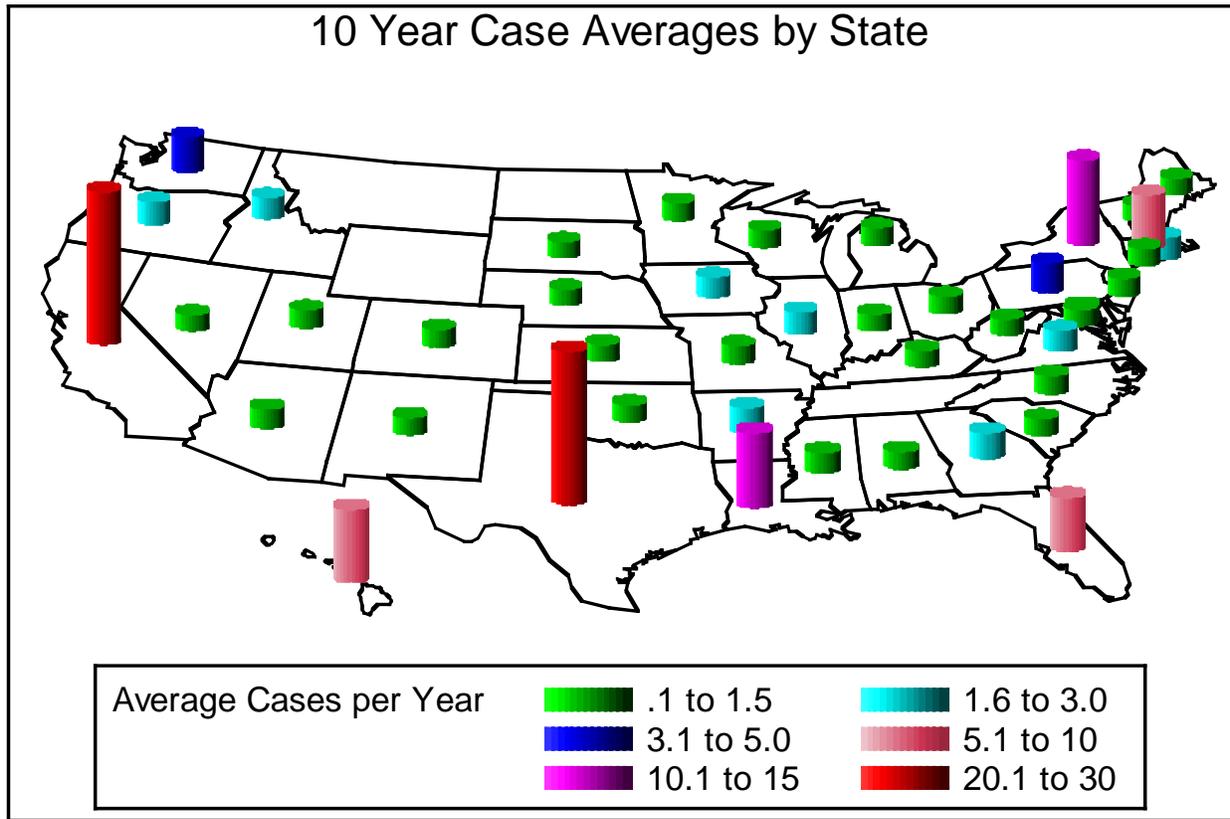


Table 2. 2006 U.S. Hansen's Disease Cases by Birth Country

Country of Birth	Frequency	Percent
(Missing)	1	0.73
AMERICAN SAMOA	1	0.73
BRAZIL	18	13.14
CHINA	1	0.73
COLOMBIA	1	0.73
CUBA	3	2.19
DOMINICAN REPUBLIC	1	0.73
ECUADOR	1	0.73
FIJI	1	0.73
GUYANA	2	1.46
HAITI	3	2.19
INDIA	9	6.57
INDONESIA	2	1.46
JAMAICA	1	0.73
KAMPUCHEA	1	0.73
LAOS	1	0.73
MEXICO	20	14.60
MICRONESIA	5	3.65
PARAGUAY	1	0.73
PHILIPPINES	22	16.06
PUERTO RICO	1	0.73
SOMALIA	1	0.73
SUDAN	1	0.73
SURINAME	1	0.73
TRUST TERRITORY	11	8.03
UNITED STATES	21	15.33
VIETNAM	6	4.38

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

Birth Country	Frequency	Percent
(Missing)	11	0.90
ALBANIA	1	0.08
AMERICAN SAMOA	9	0.73
ARGENTINA	1	0.08
BAHAMAS	1	0.08
BANGLADESH	7	0.57
BOLIVIA	1	0.08
BRAZIL	57	4.64
BURMA	5	0.41
CAPE VERDE	3	0.24
CHILE	1	0.08
CHINA	8	0.65
COLOMBIA	8	0.65
CONGO	1	0.08
COSTA RICA	3	0.24
CUBA	34	2.77
DOMINICAN REPUBLIC	40	3.26
ECUADOR	6	0.49
EGYPT	1	0.08
EL SALVADOR	2	0.16
ETHIOPIA	2	0.16
GAMBIA	2	0.16
GUATEMALA	2	0.16
GUYANA	12	0.98
HAITI	5	0.41
HONDURAS	1	0.08
HONG KONG	2	0.16
INDIA	82	6.68

Birth Country	Frequency	Percent
INDONESIA	9	0.73
IRAN	1	0.08
IVORY COAST	1	0.08
JAMAICA	1	0.08
JAPAN	1	0.08
JORDAN	1	0.08
KAMPUCHEA	5	0.41
KENYA	2	0.16
LAOS	7	0.57
LEBANON	1	0.08
LIBERIA	4	0.33
MALAYSIA	1	0.08
MEXICO	211	17.18
MICRONESIA	43	3.50
NEW ZEALAND	1	0.08
NICARAGUA	1	0.08
NIGERIA	10	0.81
PAKISTAN	9	0.73
PAPUA NEW GUINEA	1	0.08
PARAGUAY	2	0.16
PHILIPPINES	96	7.82
PUERTO RICO	26	2.12
SENEGAL	1	0.08
SOLOMON ISLANDS	1	0.08
SOMALIA	4	0.33
SRI LANKA	2	0.16
ST CHRISTOPHER NEVIS ST KITTS	1	0.08
SUDAN	6	0.49
SURINAME	1	0.08
TAIWAN	1	0.08
THAILAND	1	0.08

Birth Country	Frequency	Percent
TRINIDAD AND TOBAGO	11	0.90
TRUST TERRITORY	27	2.20
UNITED STATES	293	23.86
UNKNOWN	91	7.41
VENEZUELA	1	0.08
VIETNAM	40	3.26
VIRGIN ISLANDS	2	0.16
WESTERN SAMOA	3	0.24

Figure 6. U.S. Hansen's Disease Cases by Ethnicity

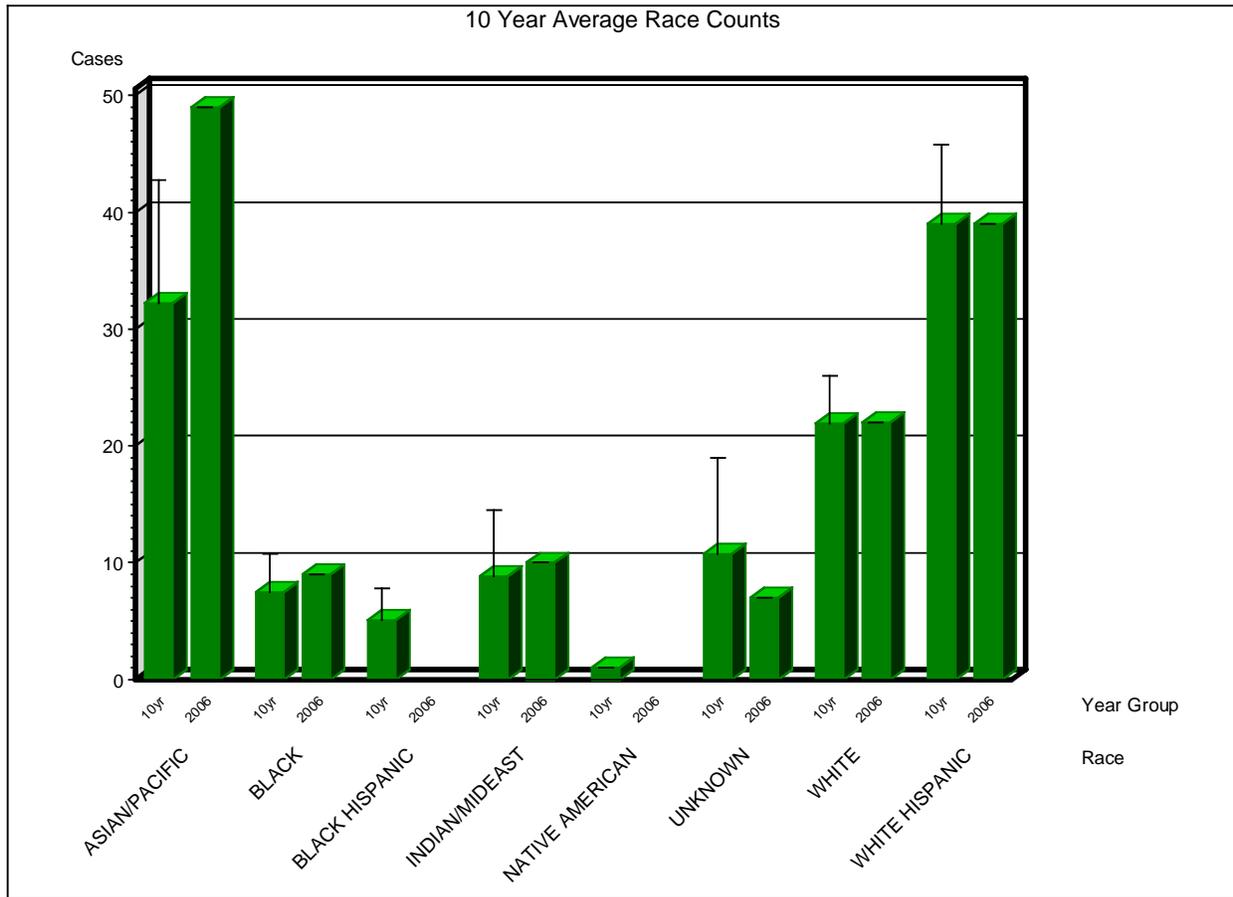


Table 4a. 2006 U.S. Hansen's Disease Cases by Diagnosis Code

Diagnosis Code	Frequency	Percent
(Missing)	1	0.73
030.0	69	50.36
030.1	38	27.74
030.2	6	4.38
030.3	12	8.76
030.8	1	0.73
030.9	10	7.30

Table 4b. Ten Year Summary U.S. Hansen's Disease Cases by Diagnosis Code

Diagnosis Code	Frequency	Percent
(Missing)	4	0.33
030.0	620	50.49
030.1	314	25.57
030.2	40	3.26
030.3	145	11.81
030.8	5	0.41
030.9	100	8.14

Table 5a. 2006 U.S. Hansen's Disease Cases by Ridley-Jopling Classification

Ridley-Jopling Class.	Frequency	Percent
(Missing)	24	16.06
Borderline	9	6.57
Borderline Lepromatous	21	15.33
Borderline Tuberculoid	20	14.60
Indeterminate	7	5.11
Lepromatous Leprosy	44	32.12
Tuberculoid	12	8.76

Table 5b. Ten Year Summary U.S. Hansen's Disease Cases by Ridley-Jopling Classification

Ridley Jopling Class.	Frequency	Percent
(Missing)	317	25.73
Borderline	83	6.76
Borderline Lepromatous	152	12.38
Borderline Tuberculoid	140	11.40
Indeterminate	41	3.34
Lepromatous Leprosy	384	31.27
Tuberculoid	111	9.04

Table 6a. 2006 U.S. Hansen's Disease Cases by WHO Classification

WHO Classification	Frequency	Percent
(Missing)	3	2.19
MULTIBACILLARY	72	52.55
PAUCIBACILLARY	62	45.26

Table 6b. Ten Year Summary U.S. Hansen's Disease Cases by WHO Classification

WHO Classification	Frequency	Percent
MULTIBACILLARY	355	65.02
PAUCIBACILLARY	191	34.98

Frequency Missing = 683

Figure 7. 2006 U.S. Hansen's Disease Cases by Classification

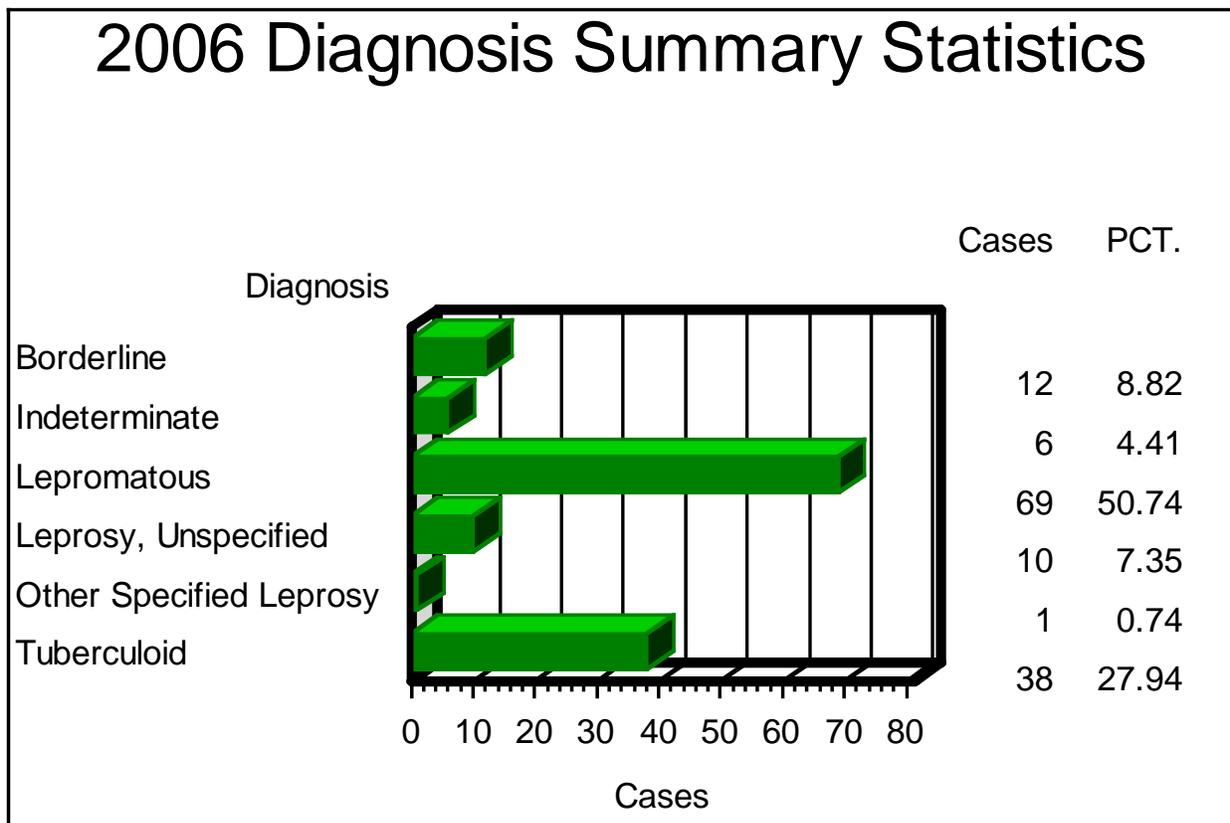


Figure 8. Ten Year Summary U.S. Hansen's Disease Cases by Classification

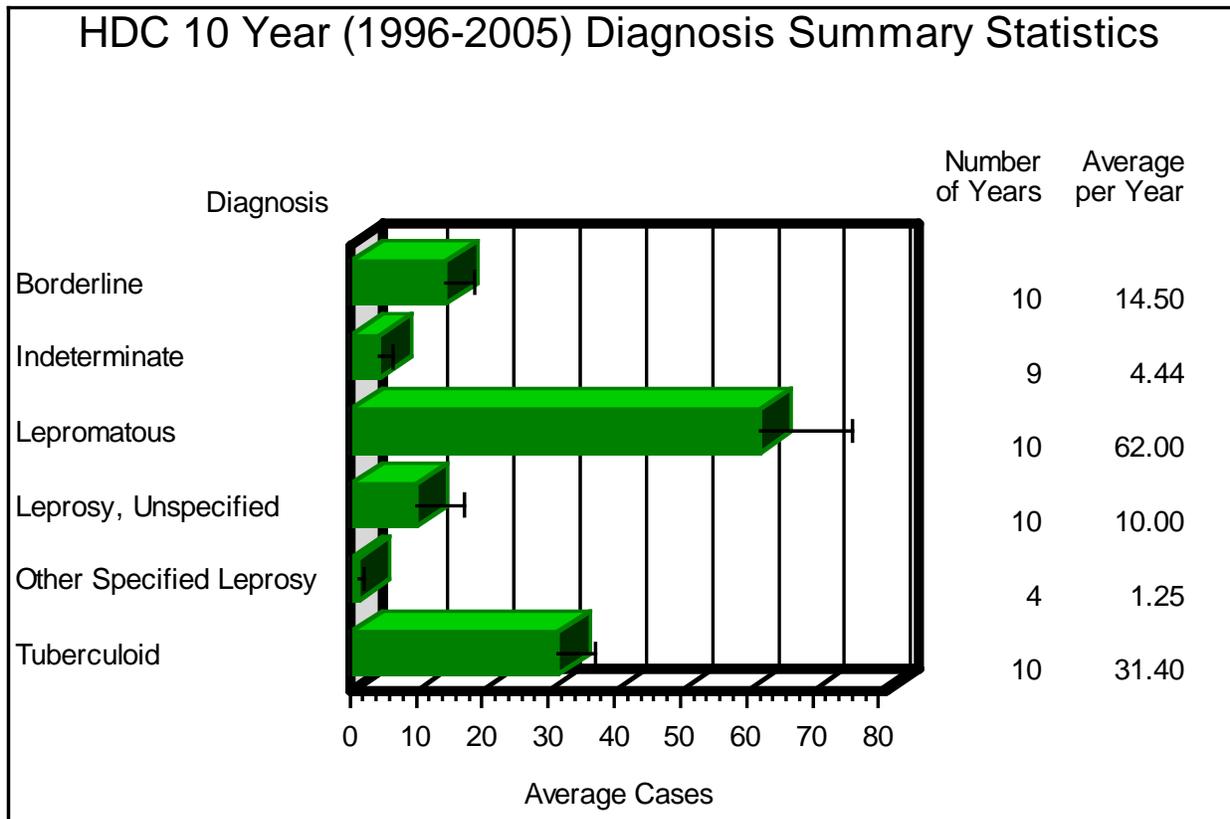


Table 7a. 2006 U.S. Hansen's Disease Cases by Gender

Gender	Frequency	Percent
FEMALE	45	32.85
MALE	92	67.15

Table 7b. Ten Year Summary U.S. Hansen's Disease Cases by Gender

Gender	Frequency	Percent
FEMALE	403	32.82
MALE	825	67.18

Figure 9. Gender of U.S. Hansen's Disease Cases

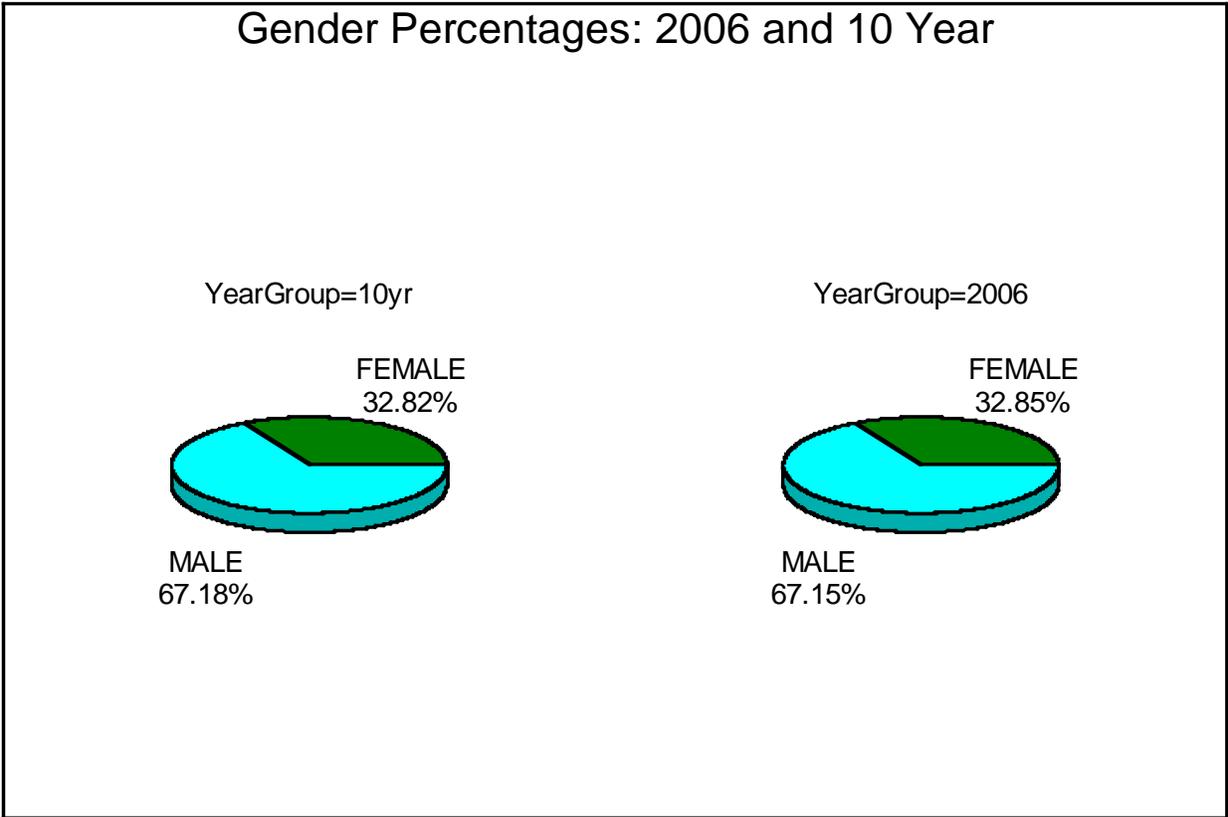


Table 8a. 2006 U.S. Hansen's Disease Case Age Distribution

Age Group	Frequency	Percent
16 to 30	27	19.71
31 to 45	39	28.47
<16	4	2.92
>45	67	48.91

Table of Age Group by Gender			
Age Group	Gender		Total
Frequency Percent Row Pct Col Pct	FEMALE	MALE	
<16	1	3	4
	0.73	2.19	2.92
	25.00	75.00	
	2.22	3.26	
16 to 30	12	15	27
	8.76	10.95	19.71
	44.44	55.56	
	26.67	16.30	
31 to 45	8	31	39
	5.84	22.63	28.47
	20.51	79.49	
	17.78	33.70	
>45	24	43	67
	17.52	31.39	48.91
	35.82	64.18	
	53.33	46.74	
Total	45	92	137
	32.85	67.15	100.0 0

Table 8b. Ten Year Summary of U.S. Hansen's Disease Case Age Distribution

Age Group	Frequency	Percent
	16 to 30	283
31 to 45	322	26.22
<16	38	3.09
>45	585	47.64

Table of Age Group by Gender			
Age Group	Gender		Total
	FEMALE	MALE	
Frequency			
Percent			
Row Pct			
Col Pct			
16 to 30	79	204	283
	6.43	16.61	23.05
	27.92	72.08	
	19.60	24.73	
31 to 45	101	221	322
	8.22	18.00	26.22
	31.37	68.63	
	25.06	26.79	
<16	17	21	38
	1.38	1.71	3.09
	44.74	55.26	
	4.22	2.55	
>45	206	379	585
	16.78	30.86	47.64
	35.21	64.79	
	51.12	45.94	
Total	403	825	1228
	32.82	67.18	100.00

Figure 10. Age Distribution of U.S. Hansen's Disease Cases

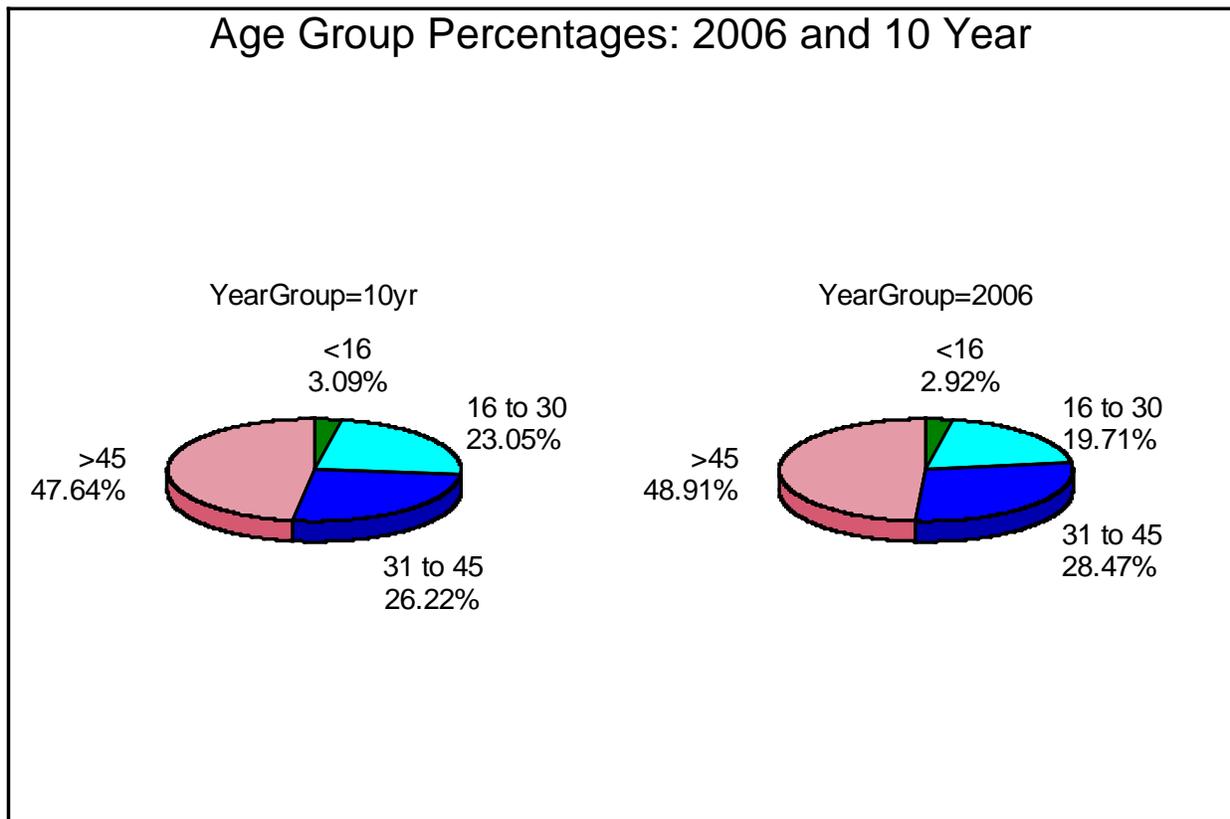


Figure 11. Trend of Endemic and non-Endemic new Hansen’s Disease case presentations.

