A Summary of Hansen's Disease in the United States-2005

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

Prepared by:
CAPT Richard Truman, Ph.D.*
Michael T. Kearney, M.S., M. Ap. Stat. **
CDR Jacqueline W. Lea, R.Ph.*

*National Hansen's Disease Program
Health Resources and Services Administration

** Consultant Biostatistician

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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) patients in the U.S. 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 healthcare agencies. Patient information is provided through delivery of the Hansen's Disease (Leprosy) 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 website at http://www.bphc.hrsa.gov/nhdp/. 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 2005 was 12,025. The following is a general demographic summary of the cases reporting in 2005.

Specific questions or other inquiries for data or analysis should be directed CAPT Richard Truman, Ph.D Rtruman@HRSA.gov.

2005 Registry Summary

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Temporal Distribution

A total of 166 cases were reported to the National Hansen's Disease Registry (NHDR) in 2005, representing a > 20% increase over the number of cases reported in the previous year (2004, n=131). This clearly reverses the declining trend in registered cases seen in recent years (Figure 1). Temporal variation in presentation is not uncommon with chronic diseases and can be influenced by a variety of factors. The decline in case registrations seen in the previous three years was coincident with the geographic relocation of our program from Carville, Louisiana to its current Baton Rouge campus, and it is possible that this programmatic disruption had some impact on case reporting.

The monthly number of cases registered in 2005 ranged from a low of 5 in December to a high of 33 in June (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. Among the operational concerns that might have influenced case registration in 2005 was transfer of our Registry data between incompatible computer platforms, which likely created some bottlenecks in recording. The Hansen's Disease Registry is now available as a SAS dataset, making it much easier to compare reporting trends. Comparing monthly registration trends over the last ten 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).

Geographic Distribution

HD cases were reported from 30 U.S. states and Puerto Rico in 2005 (Table 1). A ten year summary of reported cases is shown in Table 1b, and a graphical representation with comparison to the ten year trend is shown in Figures 4 and 5 respectively. California, Louisiana, Massachusetts, New York and Texas contributed the largest number of cases in 2005, and collectively accounted for 60% (100/166) of the cases registered. The predominance of these states is in keeping with the ten year trend in reporting, which also would identify Florida, Hawaii, Pennsylvania, Puerto Rico and Washington 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 2005, a total of 9 cases were reported from Hawaii and 10 from Puerto Rico. Reporting from both of these locations generally exceeds their

historical trend. Hawaiian cases were almost exclusively among immigrants and about half the increased number seen from Puerto Rico were among late reporting cases diagnosed before 2004.

A total of 45 cases were reported from Texas (24) and Louisiana (21). Though somewhat higher than usual, the combined number of cases is consistent with the historical norms from these states and about half of the cases reported were native born U.S. citizens with no residence history outside the U.S.. 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. 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 166 reported cases, 125 (75%) recorded a location other than the U.S. as their place of birth. Collectively, national origin of the cases reported in 2005 could be associated with a total of 35 different countries or territories (Table 2). Of the 35 total birth countries reported, the majority of cases (68%) presented from the U.S. (41), Mexico (32), Brazil (16), Philippines (9), Dominican Republic (8), and India (7) respectively. Another 14 cases arose from among areas in the western pacific such as the Trust Territories, Micronesia or American or Western Somoa. These same patterns are generally reflected in the ten year trend summary, except notably fewer cases are now being registered among persons immigrating from Cuba or Viet Nam (Table 3).

Race or Ethnicity

The ethnic or racial association identified by cases reporting in 2005 is shown in Figure 6. The 2005 distribution was in keeping with the ten year trend and shows a broad involvement of ethnic groups. While the largest number of our cases (61/166, 36%) identify themselves as being of Hispanic Origin, they are closely followed by Non-Hispanic Whites and Blacks (56/166, 34%), and then by Asian or Pacific Islanders (36/166, 22%). More than half (88/166) of all cases reporting in 2005 identified themselves as White.

Disease Classification

The Hansen's disease 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 leprosy (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 Leprosy Surveillance Form in the U.S. The diagnosis code distribution of classifications registered in 2005 is shown in Table 4a. The majority (131/166, 79%) of U.S. cases are coded as either 030.0 or 030.1 and correspond to either lepromatous (59%) or tuberculoid (20%) respectively. Comparing these percentages to the ten year trend of reported codes (Table 4b) shows no significant variation, and these 2005 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. 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 2005, and their ten year trends, are shown in Tables 5a and 5b respectively. Consistent with the diagnosis code data the majority (51/105) of U.S. cases are classified a lepromatous.

The WHO assess 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 2005, 112 (67.4%) of the reported cases are grouped as Multibacillary and 50 (30.4%) 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 2005 in Figure 7 and for the preceding 10 year period in Figure 8.

Age and Gender

Of the 166 cases reported to the registry in 2005, 72% (120/166) were male and 28% (46/166) 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 U.S. (Figure 9).

The age distribution of U.S. cases in 2005 is summarized in Table 8a and over the last ten years in Table 8b. Further demographic breakdown of cases by age and gender is shown in the sub-part of each table. In 2005, the age of all registrants ranged from 6 to 93 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 ten 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.

Appendices:

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

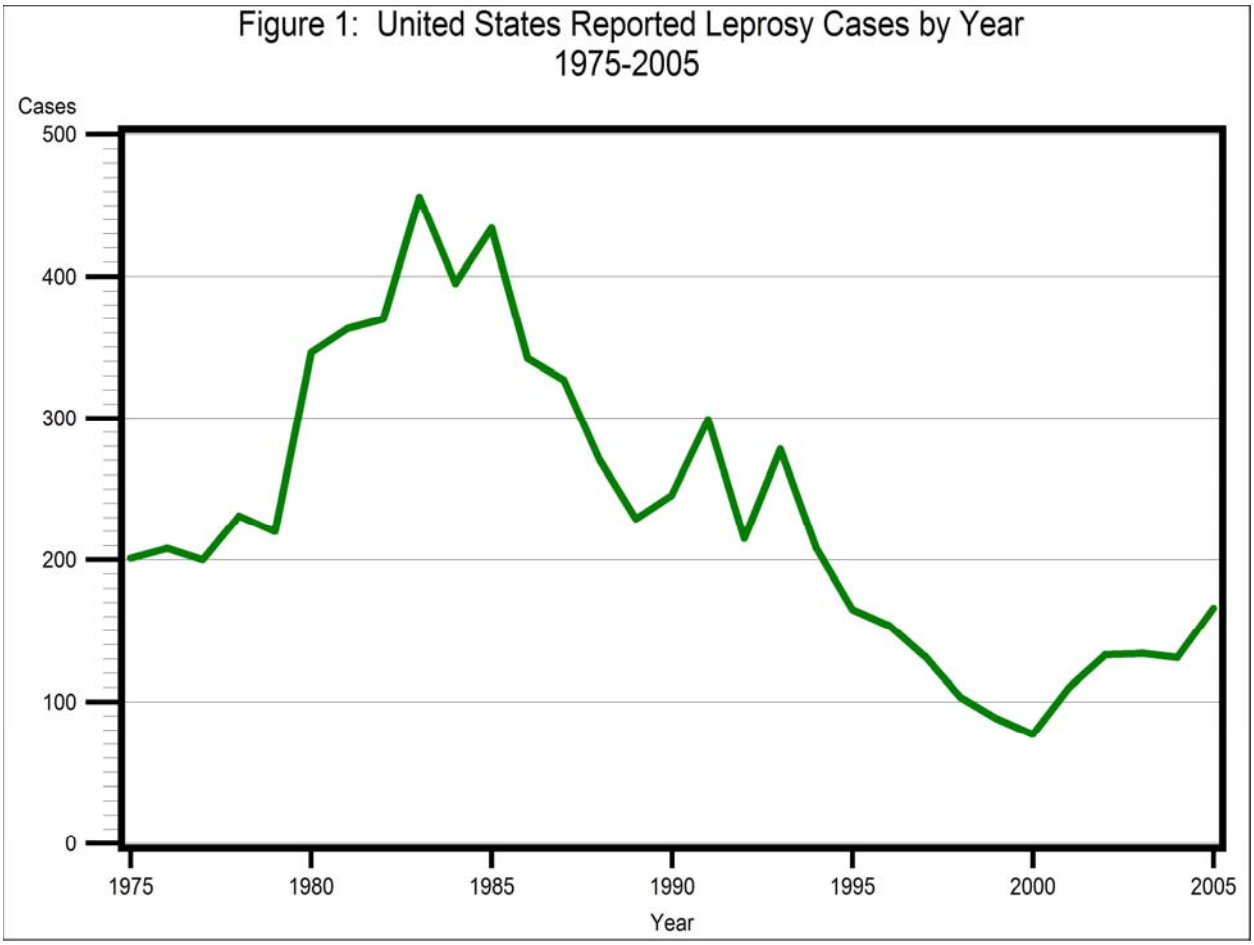

Figure 2. U.S. Reported Leprosy Cases by Month in 2005

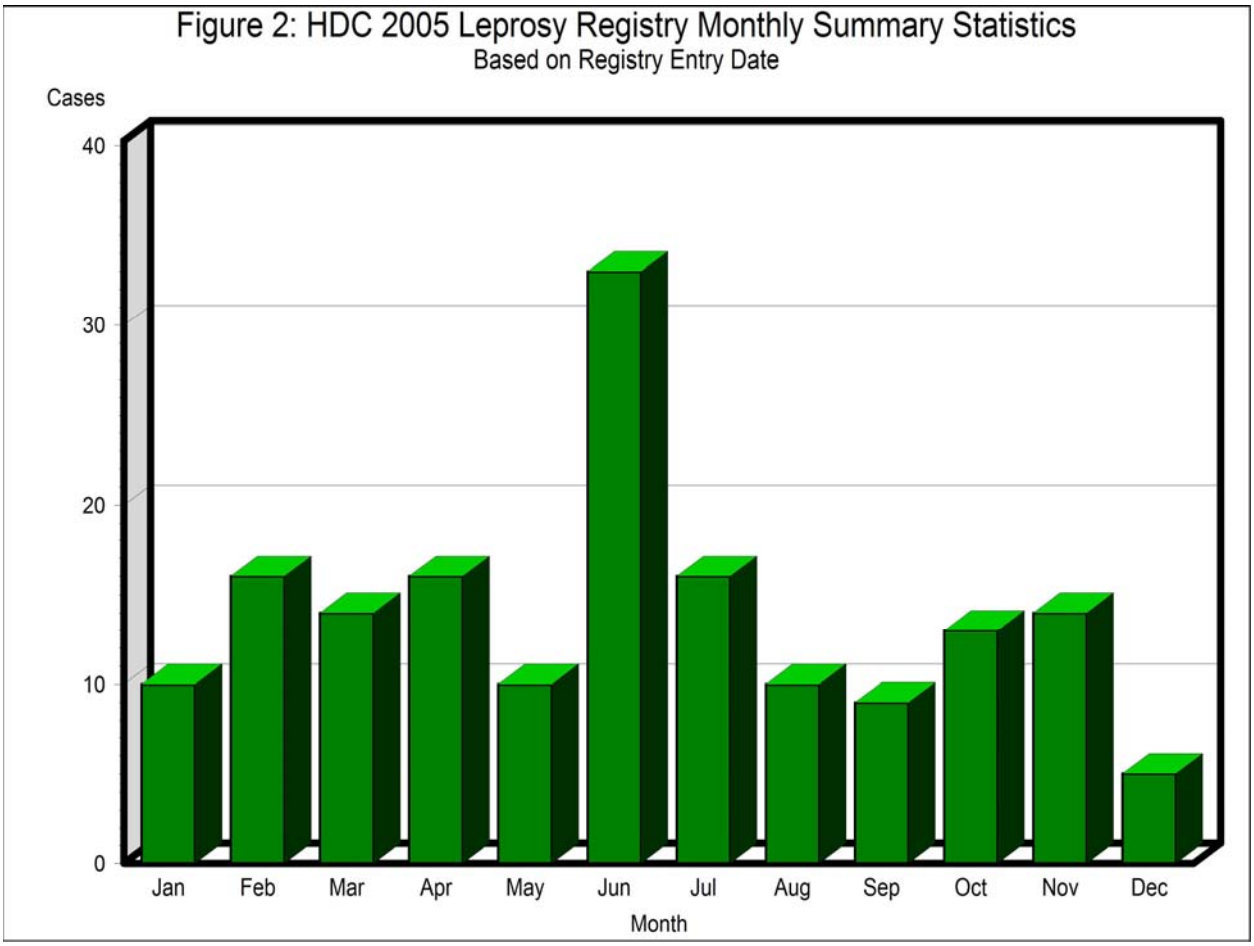

Figure 3. Ten Year U.S. Reported Leprosy Cases by Month

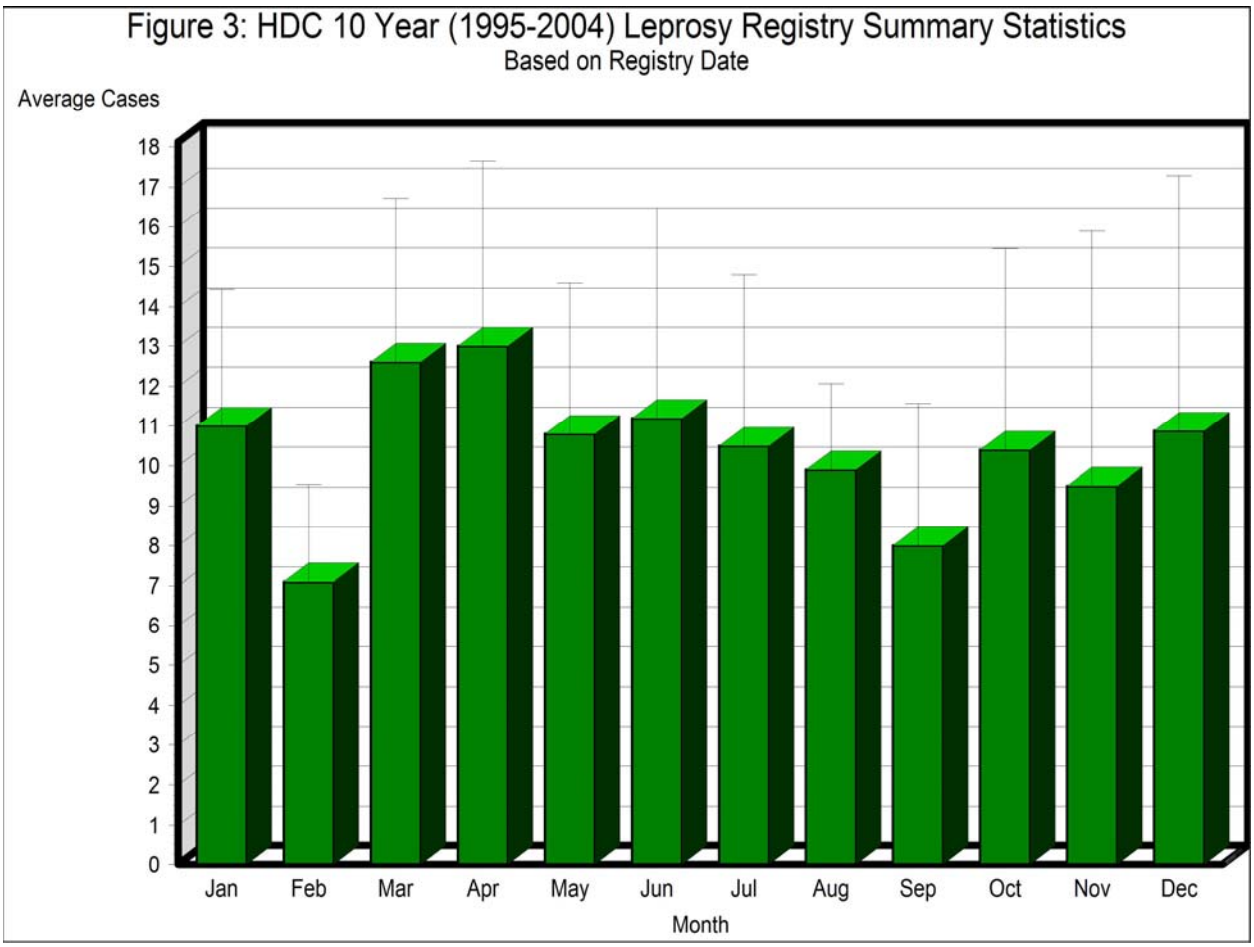

Table 1a: Reporting by U.S. State or Location

StateReporting	Frequency	Percent	Cumulative Frequency	Cumulative Percent
ARIZONA	3	1.81	3	1.81
ARKANSAS	3	1.81	6	3.61
CALIFORNIA	24	14.46	30	18.07
COLORADO	1	0.60	31	18.67
FLORIDA	4	2.41	35	21.08
GEORGIA	2	1.20	37	22.29
HAWAII	9	5.42	46	27.71
ILLINOIS	2	1.20	48	28.92
INDIANA	1	0.60	49	29.52
IOWA	2	1.20	51	30.72
KENTUCKY	1	0.60	52	31.33
LOUISIANA	21	12.65	73	43.98
MAINE	1	0.60	74	44.58
MASSACHUSETTS	19	11.45	93	56.02
MINNESOTA	2	1.20	95	57.23
MISSISSIPPI	1	0.60	96	57.83
MISSOURI	1	0.60	97	58.43
NEBRASKA	1	0.60	98	59.04
NEVADA	1	0.60	99	59.64
NEW JERSEY	3	1.81	102	61.45
NEW MEXICO	1	0.60	103	62.05
NEW YORK	12	7.23	115	69.28
OKLAHOMA	1	0.60	116	69.88
OREGON	3	1.81	119	71.69
PENNSYLVANIA	3	1.81	122	73.49
PUERTO RICO	10	6.02	132	79.52
RHODE ISLAND	2	1.20	134	80.72
SOUTH DAKOTA	1	0.60	135	81.33
TEXAS	24	14.46	159	95.78

StateReporting	Frequency	Percent	Cumulative Frequency	Cumulative Percent
VIRGINIA	1	0.60	160	96.39
WASHINGTON	6	3.61	166	100.00

Table 1b: Ten year Trend Summary of State Reporting

StateReporting	Frequency	Percent	Cumulative Frequency	Cumulative Percent
ALABAMA	4	0.38	4	0.38
ALASKA	1	0.09	5	0.47
ARIZONA	3	0.28	8	0.76
ARKANSAS	20	1.90	28	2.66
CALIFORNIA	206	19.56	234	22.22
COLORADO	6	0.57	240	22.79
CONNECTICUT	6	0.57	246	23.36
DISTRICT OF COLUMBIA	3	0.28	249	23.65
FLORIDA	66	6.27	315	29.91
GEORGIA	15	1.42	330	31.34
HAWAII	47	4.46	377	35.80
IDAHO	4	0.38	381	36.18
ILLINOIS	13	1.23	394	37.42
INDIANA	3	0.28	397	37.70
IOWA	5	0.47	402	38.18
KANSAS	1	0.09	403	38.27
KENTUCKY	1	0.09	404	38.37
LOUISIANA	95	9.02	499	47.39
MARYLAND	4	0.38	503	47.77
MASSACHUSETTS	34	3.23	537	51.00
MICHIGAN	6	0.57	543	51.57
MINNESOTA	4	0.38	547	51.95
MISSISSIPPI	7	0.66	554	52.61
MISSOURI	5	0.47	559	53.09
NEBRASKA	5	0.47	564	53.56
NEVADA	2	0.19	566	53.75
NEW HAMPSHIRE	1	0.09	567	53.85
NEW JERSEY	6	0.57	573	54.42
NEW MEXICO	1	0.09	574	54.51

StateReporting	Frequency	Percent	Cumulative Frequency	Cumulative Percent
NEW YORK	112	10.64	686	65.15
NORTH CAROLINA	4	0.38	690	65.53
OHIO	6	0.57	696	66.10
OKLAHOMA	3	0.28	699	66.38
OREGON	14	1.33	713	67.71
PENNSYLVANIA	20	1.90	733	69.61
PUERTO RICO	34	3.23	767	72.84
RHODE ISLAND	1	0.09	768	72.93
SOUTH CAROLINA	1	0.09	769	73.03
SOUTH DAKOTA	3	0.28	772	73.31
TENNESSEE	6	0.57	778	73.88
TEXAS	222	21.08	1000	94.97
UTAH	5	0.47	1005	95.44
VIRGINIA	10	0.95	1015	96.39
WASHINGTON	32	3.04	1047	99.43
WEST VIRGINIA	1	0.09	1048	99.53
WISCONSIN	4	0.38	1052	99.91
WYOMING	1	0.09	1053	100.00

Figure 4. 2005 U.S. Cases by State

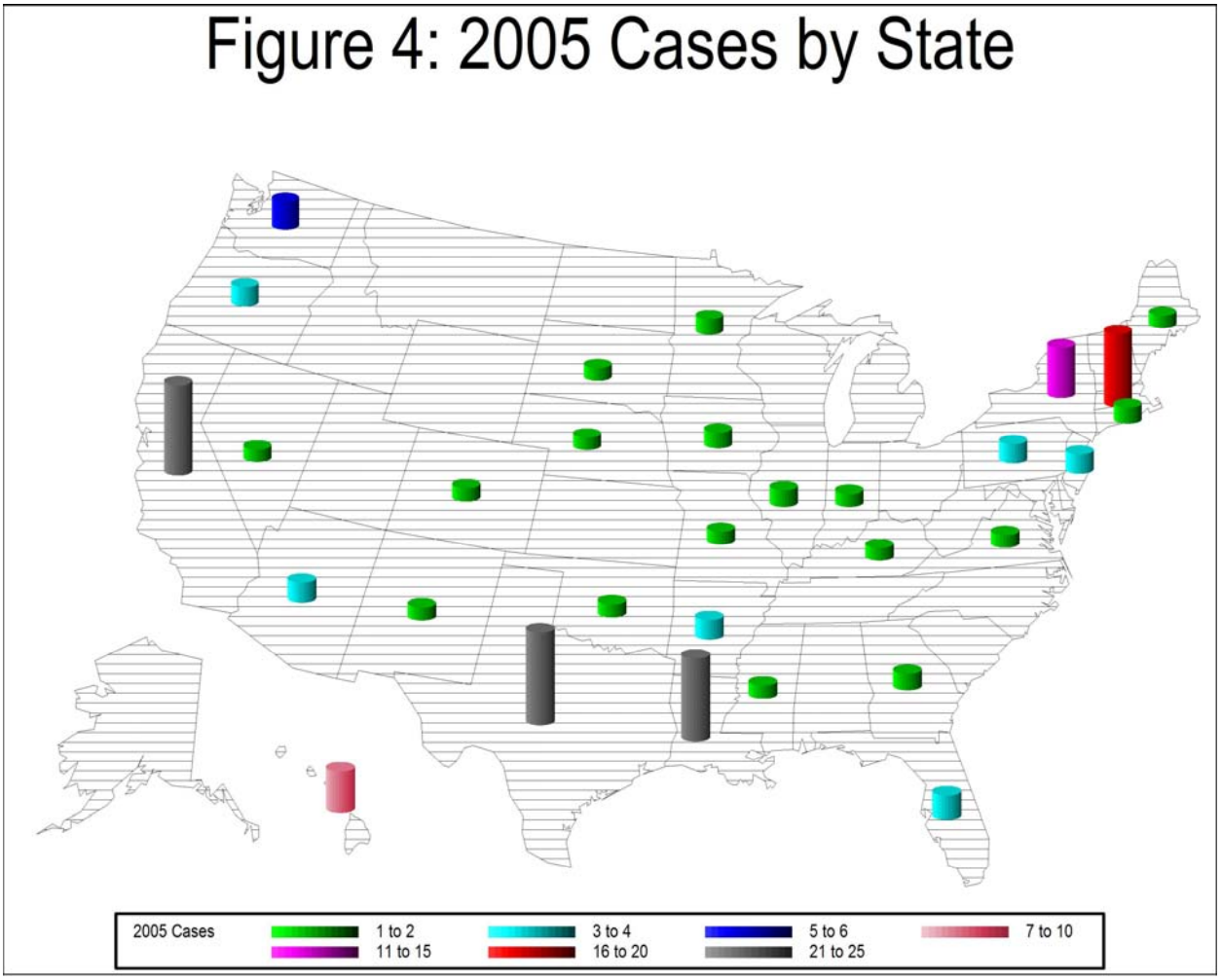

Figure 5. 10 Year Average U.S. Cases by State

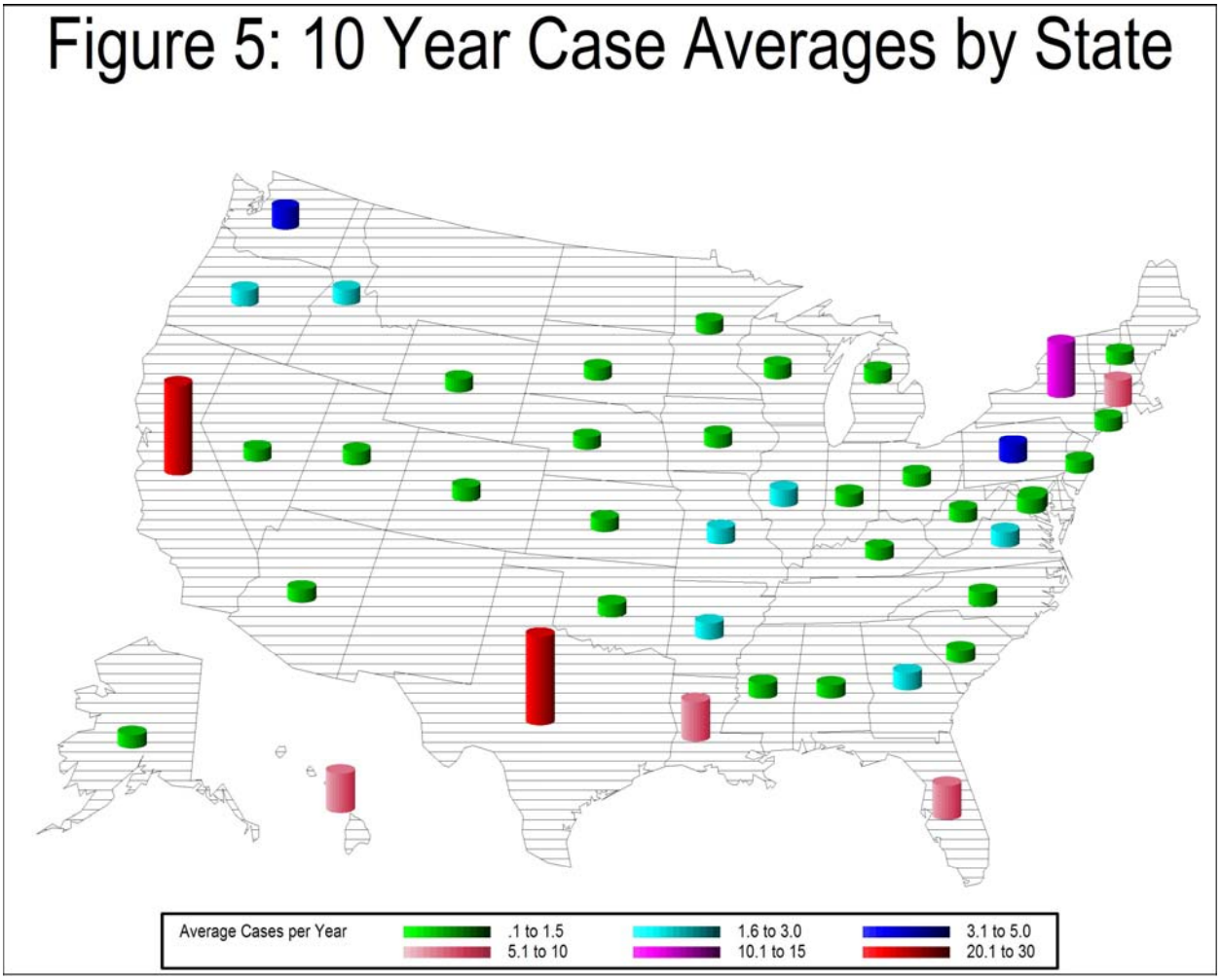

Table 2. 2005 U.S. Cases by Birth Country

CountryBirth	Frequency	Percent	Cumulative Frequency	Cumulative Percent
AMERICAN SAMOA	1	0.60	1	0.60
BAHAMAS	1	0.60	2	1.20
BANGLADESH	1	0.60	3	1.81
BRAZIL	16	9.64	19	11.45
BURMA	1	0.60	20	12.05
CAPE VERDE	1	0.60	21	12.65
COLOMBIA	4	2.41	25	15.06
CONGO	1	0.60	26	15.66
COSTA RICA	1	0.60	27	16.27
CUBA	2	1.20	29	17.47
DOMINICAN REPUBLIC	8	4.82	37	22.29
ECUADOR	1	0.60	38	22.89
EGYPT	1	0.60	39	23.49
GUATEMALA	2	1.20	41	24.70
GUYANA	2	1.20	43	25.90
HAITI	1	0.60	44	26.51
INDIA	7	4.22	51	30.72
INDONESIA	3	1.81	54	32.53
IVORY COAST	1	0.60	55	33.13
KAMPUCHEA	1	0.60	56	33.73
KENYA	2	1.20	58	34.94
LAOS	1	0.60	59	35.54
LIBERIA	2	1.20	61	36.75
MEXICO	32	19.28	93	56.02
MICRONESIA	7	4.22	100	60.24
NIGERIA	2	1.20	102	61.45
PHILIPPINES	9	5.42	111	66.87

CountryBirth	Frequency	Percent	Cumulative Frequency	Cumulative Percent
SUDAN	2	1.20	113	68.07
THAILAND	1	0.60	114	68.67
TRINIDAD AND TOBAGO	1	0.60	115	69.28
TRUST TERRITORY	5	3.01	120	72.29
UNITED STATES	41	24.70	161	96.99
VIETNAM	3	1.81	164	98.80
VIRGIN ISLANDS	1	0.60	165	99.40
WESTERN SAMOA	1	0.60	166	100.00

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

CountryBirth	Frequency	Percent	Cumulative Frequency	Cumulative Percent
ALBANIA	1	0.09	1	0.09
AMERICAN SAMOA	9	0.85	10	0.94
ARGENTINA	1	0.09	11	1.04
BAHAMAS	1	0.09	12	1.13
BANGLADESH	6	0.57	18	1.70
BOLIVIA	1	0.09	19	1.79
BRAZIL	50	4.72	69	6.51
BURMA	4	0.38	73	6.89
CAPE VERDE	4	0.38	77	7.26
CHILE	1	0.09	78	7.36
CHINA	6	0.57	84	7.92
COLOMBIA	4	0.38	88	8.30
COSTA RICA	2	0.19	90	8.49
CUBA	33	3.11	123	11.60
DOMINICAN REPUBLIC	34	3.21	157	14.81
ECUADOR	5	0.47	162	15.28
EL SALVADOR	3	0.28	165	15.57
ETHIOPIA	2	0.19	167	15.75
GAMBIA	2	0.19	169	15.94
GUYANA	9	0.85	178	16.79
HAITI	4	0.38	182	17.17
HONDURAS	1	0.09	183	17.26
HONG KONG	2	0.19	185	17.45
INDIA	76	7.17	261	24.62
INDONESIA	5	0.47	266	25.09
IRAN	1	0.09	267	25.19
JAMAICA	1	0.09	268	25.28

CountryBirth	Frequency	Percent	Cumulative Frequency	Cumulative Percent
JORDAN	1	0.09	269	25.38
KAMPUCHEA	7	0.66	276	26.04
KENYA	1	0.09	277	26.13
LAOS	8	0.75	285	26.89
LEBANON	1	0.09	286	26.98
LIBERIA	1	0.09	287	27.08
MALAYSIA	1	0.09	288	27.17
MEXICO	186	17.55	474	44.72
MICRONESIA	38	3.58	512	48.30
NICARAGUA	1	0.09	513	48.40
NIGERIA	9	0.85	522	49.25
PAKISTAN	6	0.57	528	49.81
PAPUA NEW GUINEA	1	0.09	529	49.91
PARAGUAY	3	0.28	532	50.19
PHILIPPINES	80	7.55	612	57.74
PUERTO RICO	22	2.08	634	59.81
SENEGAL	1	0.09	635	59.91
SOLOMON ISLANDS	1	0.09	636	60.00
SOMALIA	3	0.28	639	60.28
SPAIN	1	0.09	640	60.38
SRI LANKA	2	0.19	642	60.57
ST CHRISTOPHER NEVIS ST KITTS	1	0.09	643	60.66
SUDAN	4	0.38	647	61.04
SURINAME	1	0.09	648	61.13
TAIWAN	1	0.09	649	61.23
TRINIDAD AND TOBAGO	11	1.04	660	62.26
TRUST TERRITORY	22	2.08	682	64.34
UNITED STATES	296	27.92	978	92.26
UNKNOWN	42	3.96	1020	96.23
VENEZUELA	1	0.09	1021	96.32

CountryBirth	Frequency	Percent	Cumulative Frequency	Cumulative Percent
VIETNAM	35	3.30	1056	99.62
VIRGIN ISLANDS	2	0.19	1058	99.81
WESTERN SAMOA	2	0.19	1060	100.00

Figure 6. U.S. Cases by Ethnicity

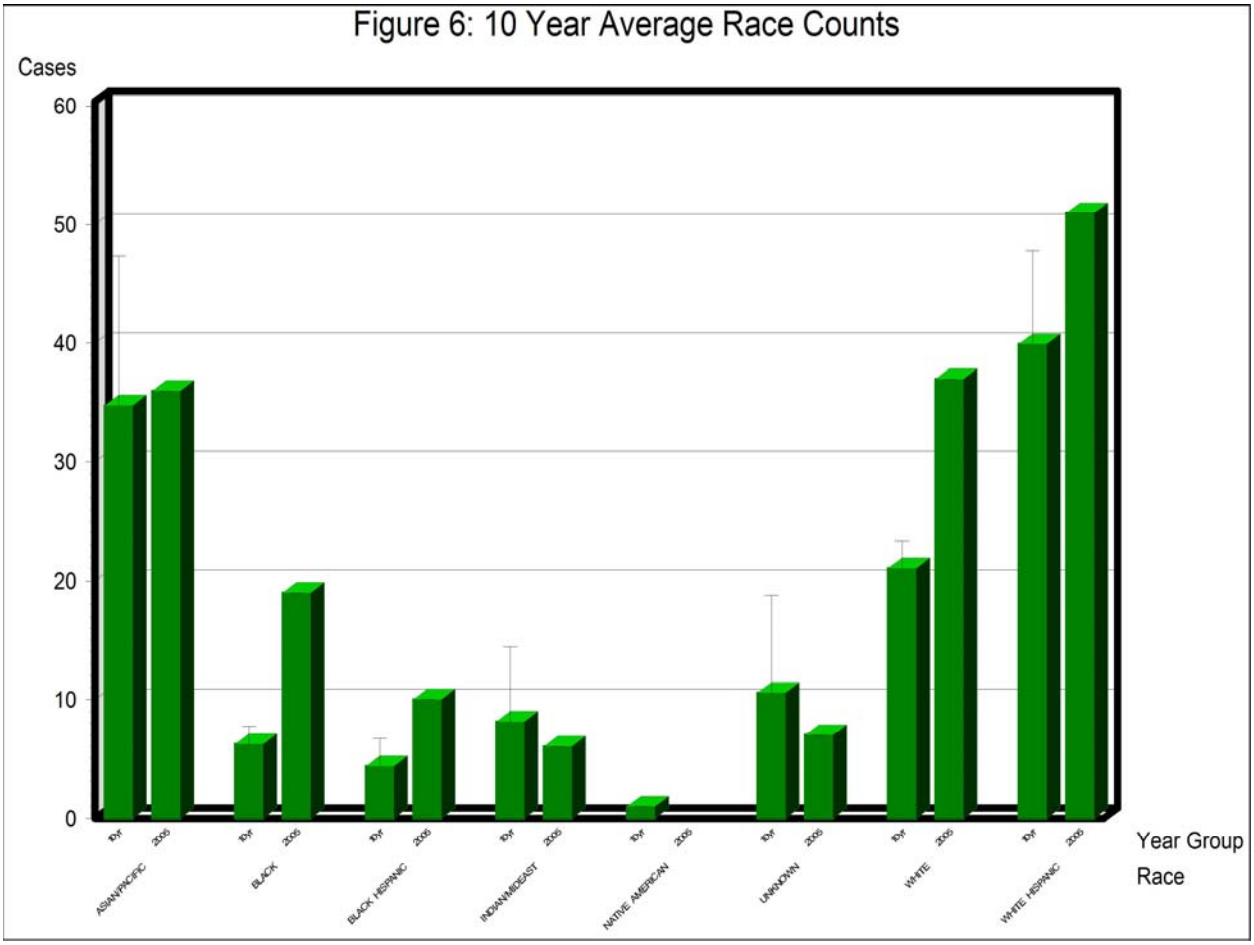

Table 4a. 2005 U.S. Cases by Diagnosis Code

HDDiagCode	Frequency	Percent	Cumulative Frequency	Cumulative Percent
030.0	98	60.49	98	60.49
030.1	33	20.37	131	80.86
030.2	10	6.17	141	87.04
030.3	14	8.64	155	95.68
030.8	1	0.62	156	96.30
030.9	6	3.70	162	100.00

Table 4b. Ten Year Summary U.S. Cases by Diagnosis Code

HDDiagCode	Frequency	Percent	Cumulative Frequency	Cumulative Percent
030.0	562	52.87	562	52.87
030.1	288	27.09	850	79.96
030.2	37	3.48	887	83.44
030.3	133	12.51	1020	95.95
030.8	2	0.19	1022	96.14
030.9	41	3.86	1063	100.00

Table 5a. 2005 U.S. Cases by Ridley-Jopling Classification

HDClass	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Borderline	4	3.81	4	3.81
Borderline Lepromatous	19	18.10	23	21.90
Borderline Tuberculoid	15	14.29	38	36.19
Indeterminate	11	10.48	49	46.67
Lepromatous Leprosy	51	48.57	100	95.24
Tuberculoid	5	4.76	105	100.00

Frequency Missing = 61

Table 5b. Ten Year Summary U.S. Cases by Ridley-Jopling Classification

HDClass	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Borderline	84	9.87	84	9.87
Borderline Lepromatous	147	17.27	231	27.14
Borderline Tuberculoid	126	14.81	357	41.95
Inactive	1	0.12	358	42.07
Indeterminate	34	4.00	392	46.06
Lepromatous Leprosy	350	41.13	742	87.19
Tuberculoid	109	12.81	851	100.00

Frequency Missing = 213

Table 6a. 2005 U.S. Cases by WHO Classification

InitBactIndex	Frequency	Percent	Cumulative Frequency	Cumulative Percent
MULTIBACILLARY	51	69.86	51	69.86
PAUCIBACILLARY	22	30.14	73	100.00

Frequency Missing = 93

Table 6b. Ten Year Summary U.S. Cases by WHO Classification

InitBactIndex	Frequency	Percent	Cumulative Frequency	Cumulative Percent
MULTIBACILLARY	335	65.05	335	65.05
PAUCIBACILLARY	180	34.95	515	100.00

Frequency Missing = 549

Figure 7. 2005 U.S. Cases by Classification

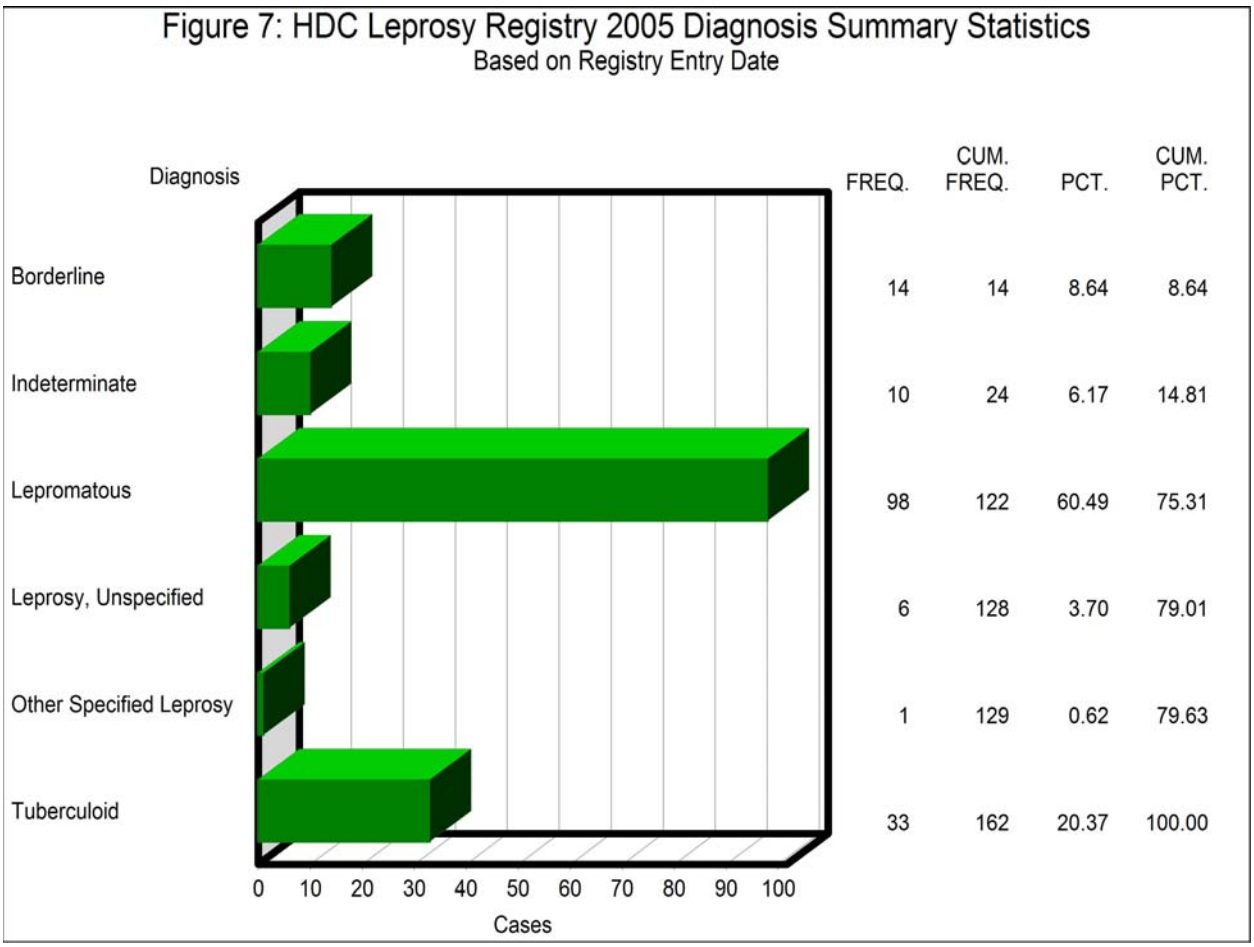

Figure 8. Ten Year Summary U.S. Cases by Classification

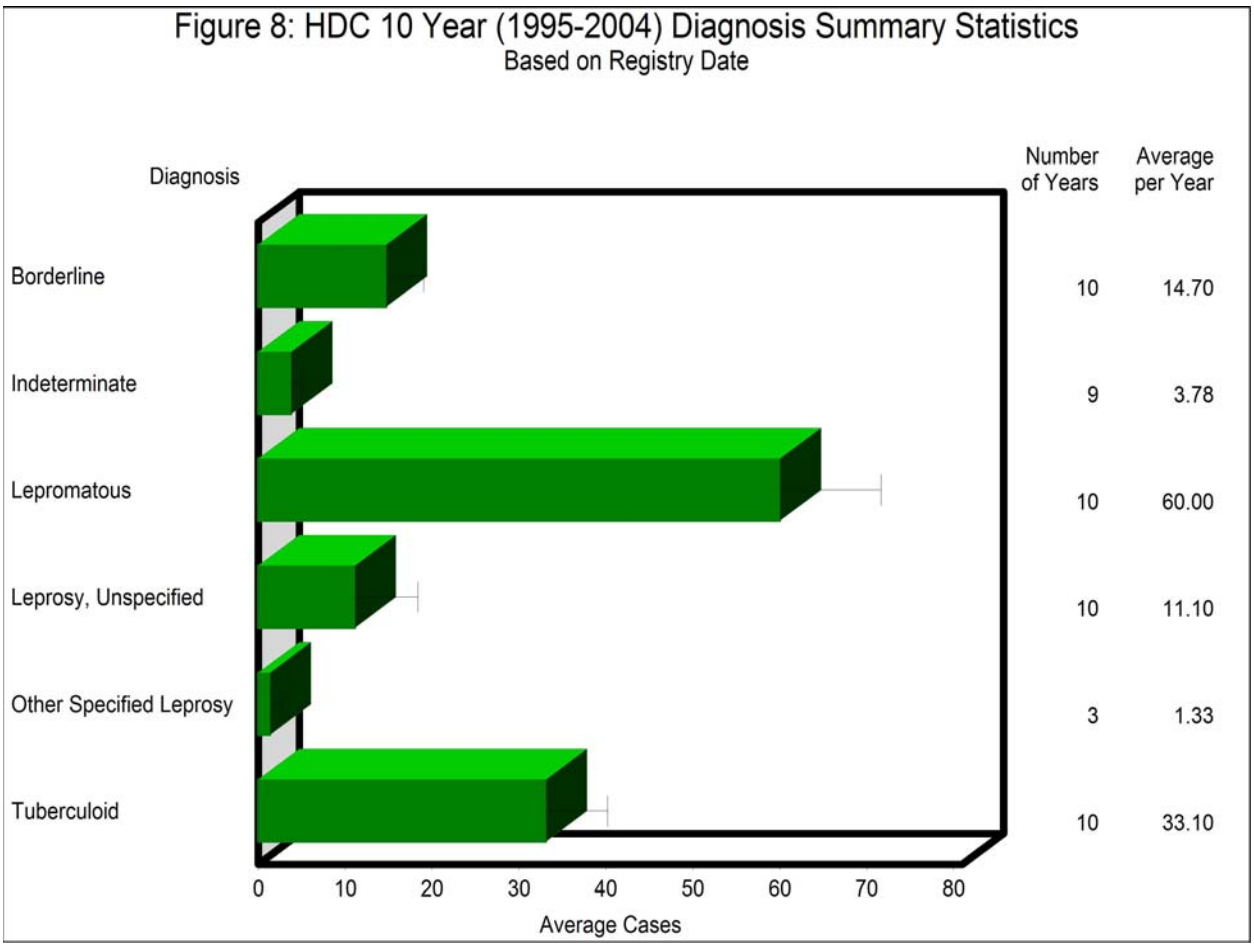

Table 7a. 2005 U.S. Cases by Gender

Gender	Frequency	Percent	Cumulative Frequency	Cumulative Percent
FEMALE	46	27.71	46	27.71
MALE	120	72.29	166	100.00

Table 7b. Ten Year Summary U.S. Cases by Gender

Gender	Frequency	Percent	Cumulative Frequency	Cumulative Percent
FEMALE	411	33.50	411	33.50
MALE	816	66.50	1227	100.00

Figure 9. Gender of U.S. Cases

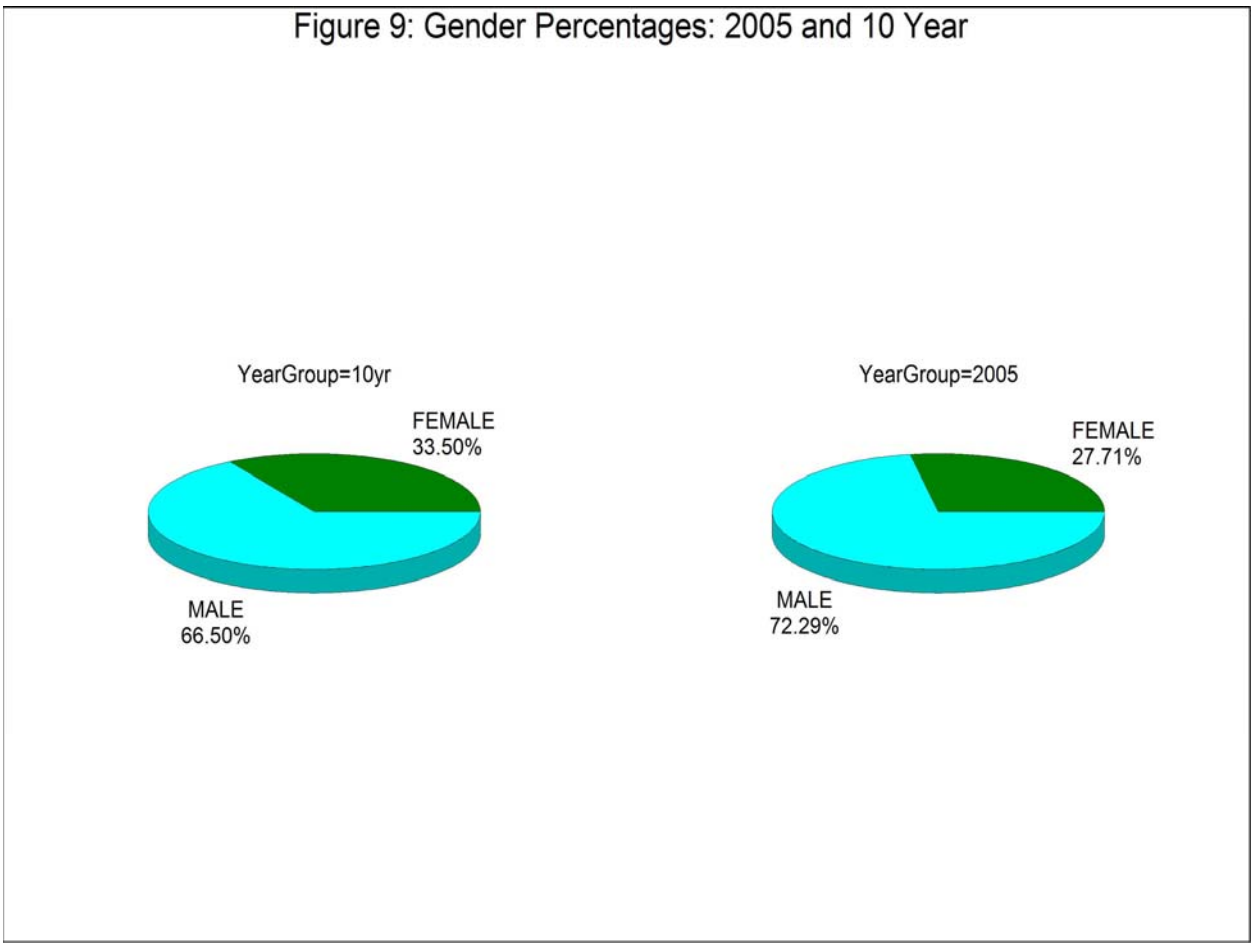

Table 8a. 2005 U.S. Case Age Distribution

agegroup	Frequency	Percent	Cumulative Frequency	Cumulative Percent
<16	7	4.22	7	4.22
16 to 30	49	29.52	56	33.73
31 to 45	46	27.71	102	61.45
>45	64	38.55	166	100.00

Table of agegroup by Gender			
agegroup	**Gender**		
Frequency Percent Row Pct Col Pct	**FEMALE**	**MALE**	**Total**
<16	2 1.20 28.57 4.35	5 3.01 71.43 4.17	7 4.22
16 to 30	12 7.23 24.49 26.09	37 22.29 75.51 30.83	49 29.52
31 to 45	13 7.83 28.26 28.26	33 19.88 71.74 27.50	46 27.71
>45	19 11.45 29.69 41.30	45 27.11 70.31 37.50	64 38.55
Total	46 27.71	120 72.29	166 100.00

Table 8b. Ten Year Summary of U.S. Case Age Distribution

Gender	Frequency	Percent	Cumulative Frequency	Cumulative Percent
FEMALE	411	33.50	411	33.50
MALE	816	66.50	1227	100.00

Table of agegroup by Gender			
agegroup	**Gender**		
Frequency Percent Row Pct Col Pct	**FEMALE**	**MALE**	**Total**
<16	18 1.47 50.00 4.38	18 1.47 50.00 2.21	36 2.93
16 to 30	73 5.95 27.44 17.76	193 15.73 72.56 23.65	266 21.68
31 to 45	101 8.23 31.27 24.57	222 18.09 68.73 27.21	323 26.32
>45	219 17.85 36.38 53.28	383 31.21 63.62 46.94	602 49.06
Total	411 33.50	816 66.50	1227 100.00

Frequency Missing = 829

Figure 10. Age Distribution of U.S. Cases