A Summary of Hansen's Disease in the United States-2004

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Introduction

The National Hansen's Disease Program's (NHDP) mission is to conduct leprosy research, educate patients and health care providers about the disease, and 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 useful information for epidemiological studies, administrative reports, and clinical, rehabilitative and laboratory research.

Data are collected through the cooperative efforts of health care providers and a network of state and local healthcare agencies. Patient information is collected by the health care provider with 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 is also reported by various state and local government agencies through the surveillance form.

Because HD is a notifiable disease, registry data is statistically analyzed and reported to the Centers for Disease Control and Prevention (CDC). As requested, summary reports are also provided to other federal agencies for administrative and funding purposes, as well as to state and local agencies. Numerous clinical, epidemiological, and academic researchers request customized reports pertinent to their specific interests.

2004 Registry Summary

Temporal Distribution

In 2004 a total of 131 Hansen's disease cases were reported to the National Hansen's Disease Registry (NHDR), representing a 2.2% decrease in the number of cases (n=134) reported in 2003. The monthly number of cases reported ranged from zero in December to a maximum of 24 (18.3%) cases in April. Table 1 and the chart in Appendix 1 illustrate this monthly distribution.

2004 Registered Leprosy Cases by Month		
MONTH	CASES	PERCENT
JAN	18	13.7%
FEB	10	7.6%
MAR	17	13.0%
APR	24	18.3%
MAY	11	8.4%
JUN	7	5.3%
JUL	7	5.3%
AUG	9	6.9%
SEP	15	11.5%
OCT	4	3.1%
NOV	9	6.9%
TOTAL	131	100.00%

Table 1

The temporal distribution of these cases is not uniform with just over two-thirds of the cases (n=94, 71.8%) being reported in the first seven months of the year. A similar phenomenon was observed in the previous three years with 83%, 77%, and 77% of the cases reported for the same period respectively for 2001-2003. Because the month in which a newly diagnosed case is reported generally coincides with the month of diagnosis, this skewness of the temporal distribution may suggest some seasonality for these cases. Of the 131 new cases reported to the registry, sixty-nine were newly diagnosed in 2004. Forty-five (65%) of these cases were reported in the first seven months of the year. While an analysis of this temporal distribution of cases reported from 1894-2004 does not support this notion of seasonality, an average of 77% of the new cases have been reported in the first seven months of the last four years. The similarity of these distributions may signal a newly developing trend in more recent years. Factors that may be causing this non-uniformity are unknown, but may relate to non-uniform immigration patterns, since foreign born cases make up the majority of newly diagnosed and reported cases.

Geographic Distribution of Cases

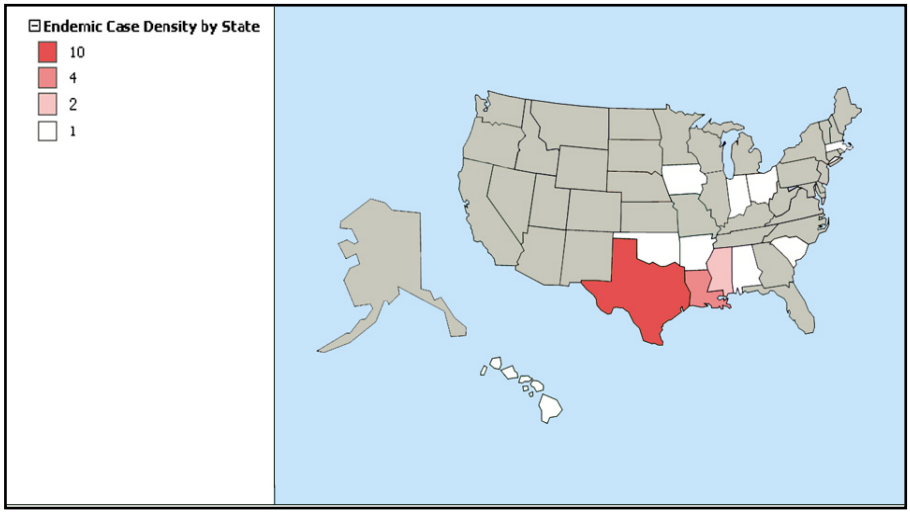
Leprosy cases were reported from 23 states and Puerto Rico in 2004. The table and corresponding density map in Appendix 2 depict the geographic case reporting distribution in 2004. Although Hawaii reported the most cases in 2004 (n=27, 20.6%), seventeen were cases that were not reported timely in 2003. Texas (n=24, 18.3%), California (n=23, 17.6%), New York (n=17, 13.0%), and Hawaii (n=10 actual 2004 cases, 7.6%) collectively reported 74 cases representing 56.5% of the total. Other than Texas and Louisiana, which have a larger number of indigenous cases, the cases reported from all other states are primarily due to immigrant settlement.

Of the 131 reported cases, 106 (80.9%) were individuals born in 24 foreign countries. The table in Appendix 3 shows the distribution by country of birth. Of the 25 reported birth countries, the six countries of the United States, Mexico, Micronesia, Brazil, the Philippines, and the Trust Territories represent approximately three-fourths (71.8%) of the total cases. Because Hawaii reported a large number of 2003 cases in 2004, the birth country totals for Micronesia and the Trust Territories are over-represented. Historical patterns show that individuals immigrating from these two countries often enter the U.S. through Hawaii.

There were 25 U.S. endemic cases born in 12 different states in 2004. Table 2 and the corresponding map illustrate the distribution of these cases by state of birth.

2004 U.S. Native Born Leprosy Cases by State of Birth	
TEXAS	10
LOUISIANA	4
MISSISSIPPI	2
ALABAMA	1
ARKANSAS	1
HAWAII	1
INDIANA	1
IOWA	1
MASSACHUSETTS	1
OHIO	1
OKLAHOMA	1
SOUTH CAROLINA	1
TOTAL	25

Table 2



Historically, there has always been an association between the incidence of Hansen's disease in the United States and geographic location, with a vast majority of the cases being reported from the gulf coastal states. In 2004 the cases listing the three gulf coastal states of Texas, Louisiana, and Mississippi as the birth state represented 64% of the endemic cases. However, the bulk of these cases are attributed to Louisiana and Texas. As in 2003 where Texas and Louisiana together represented 58% of native-born leprosy cases, these two states accounted for 56% of such cases in 2004. Furthermore, on a population adjusted basis, Louisiana has a very disproportionate number of endemic cases.

Distribution of Cases by Race and Ethnicity, Age and Gender

Table 3 summarizes the distribution of the 2004 reported cases by race and ethnicity. These data are also graphically represented in Appendix 4.

2004 Reported Hansen's Disease Cases by Race and Ethnicity		
ASIAN OR PACIFIC ISLANDER	45	34.4%
BLACK, NOT OF HISPANIC ORIGIN	10	7.6%
HISPANIC, BLACK	2	1.5%
HISPANIC, WHITE	44	33.6%
INDIAN, MIDDLE EASTERNER	6	4.6%
NOT SPECIFIED/UNKNOWN	4	3.1%
WHITE, NOT OF HISPANIC ORIGIN	20	15.3%
TOTAL	131	100.0%

Table 3

While the Asian or Pacific Islander group represented the largest number of cases (n=45, 34.4%), this statistic is again distorted by the over-reporting of the 2003 Hawaii cases. From 2001 through 2003, White Hispanics have comprised the largest ethnic group ranging from 31.8%-36.6% of reported cases. With White Hispanics accounting for 33.6% of the total cases, this trend most certainly continued in 2004, but is masked by the 2003 Hawaii cases. It is anticipated that the White Hispanic cases will continue to represent the largest ethnic group reported annually, and will soon supplant the Asian or Pacific Islander group as the largest race/ethnicity group in the registry over all time. This is attributed to the facts that the vast majority of new cases are foreign born, and Mexico is the predominant country of birth for such cases. This distribution, however, can change dramatically if there are significant shifts in immigration patterns to other highly endemic countries. With the exception of the White, Not of Hispanic Origin group, the other groups primarily represent foreign born individuals. However, nearly two-thirds (n=16, 64%) of the endemic cases are racially classified by the White, Not of Hispanic Origin category.

Of the 131 cases reported to the registry in 2004, 87 (66%) were male and 44 (34%) were female (see Appendix 5). Although 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 for the 2004 cases and in all U.S. cases reported through 2004 (1.8:1, n= 11,848).

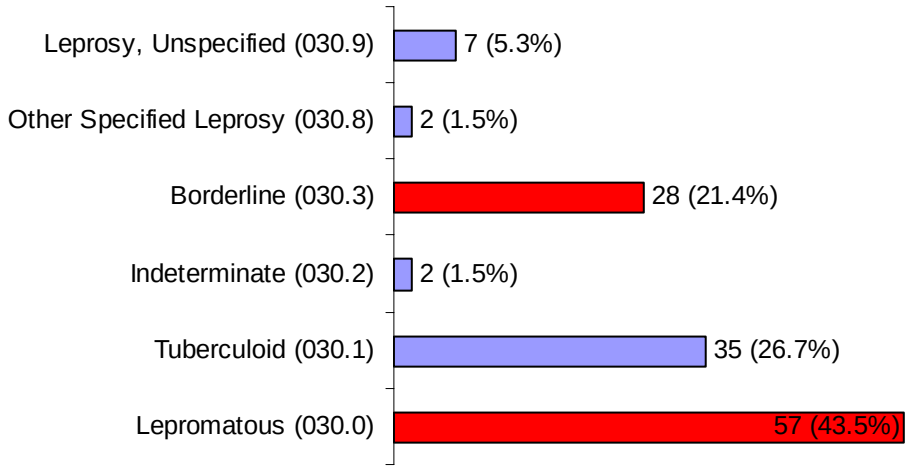
The age distribution of the sample is summarized by the graph and age at diagnosis boxplot in Appendix 6. For the cases reported to the registry in 2004, the age at diagnosis ranged from 6 to 82 years with a mean age of 40.6 ± 19.0 years. However, because Hansen's disease is not prevalent in the very young, the median age of 37.5 years is a more reliable estimator of the middle of the distribution. The middle 50% of

the 2003 cases have a diagnosis age between 26.2 and 55.7 years. Interestingly, for the 25 reported endemic cases in 2004, the median age at diagnosis was 56.8 years of age which was significantly different from the median age for foreign born cases (31.5 years, $p<0.001$). The difference in the median age at diagnosis for the endemic cases might be attributed to race/ethnicity differences, since approximately two-thirds (64%) of the 2004 endemic cases are classified as White, Non-Hispanic. Another explanation might be that individuals from other highly endemic countries immigrate to this country at a very young age.

Reported Case Distribution by Disease Classification

The Hansen's disease surveillance form provides for initial classification of the disease into one of six categories which correspond to the universally used ICD-9-CM diagnosis codes for leprosy (030.0-030.3, 030.8, and 030.9). The following chart quantifies the cases reported to the registry in 2004 by disease type.

2004 Registered Leprosy Cases by ICD-9-CM Diagnosis Code (n=131)



A category of multibacillary cases can be created by combining the borderline and lepromatous classes. Likewise, paucibacillary cases can be identified by grouping the remaining categories. For 2004, 85 (64.8%) and 46 (35.1%) of the reported cases are grouped as multibacillary and paucibacillary respectively. The table in Appendix 7 provides the typing of these cases using the Ridley-Jopling classification, but the accuracy of these data is questionable. Many clinicians often do not know the Ridley-Jopling classification when the surveillance form is completed (n=60), and most are probably unfamiliar with the leprosy spectrum.

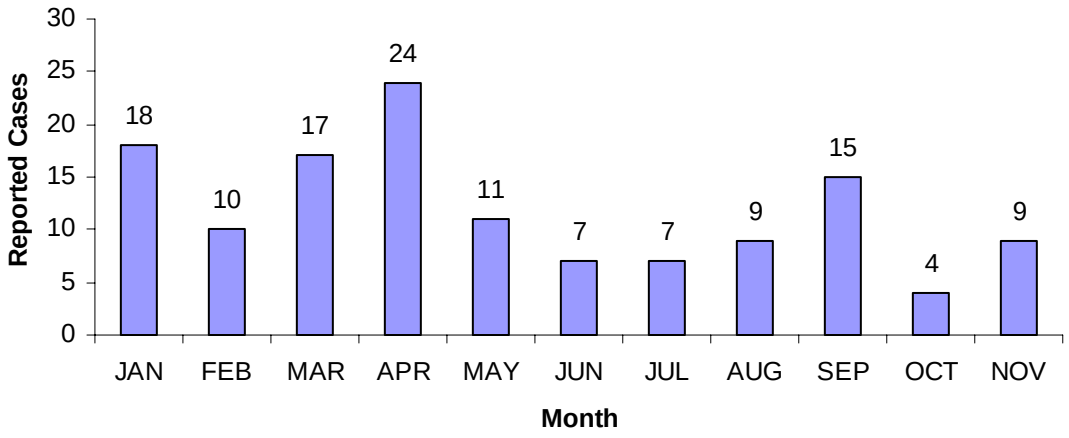
Historical Trend of Hansen's Disease in the United States

The table and corresponding graph in Appendix 8 shows the number of cases reported to the registry over the past 30 years. With the exception of the period from 1978-1988 when a large number of Indo-Chinese refugees with Hansen's disease entered the country, the number of reported cases has remained relatively

constant at approximately 130-150 new cases each year. During this thirty-year period the average number of cases reported yearly is 235.5, but this annual mean falls to 122.7 over the past decade. This decrease in reported U.S. cases since the early 1990's is due to changes in immigration patterns, and a significant decline in the number of cases reported worldwide. Although the number of endemic cases is stubbornly stable at approximately 25-30 new cases a year, the incidence of Hansen's disease in native-born Americans continues to be a rarity. Unless immigration patterns from areas of the world where leprosy is endemic changes dramatically, the number of new cases see in this country is expected to be relatively constant in the future.

Appendix 1

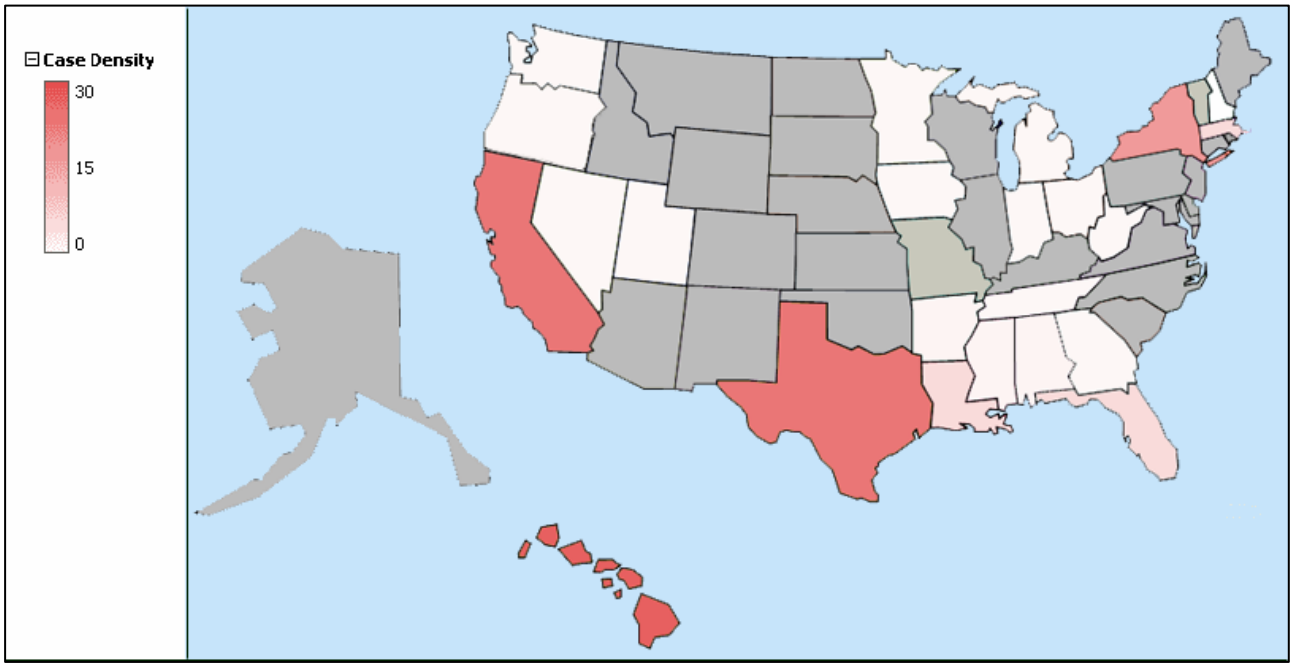
2004 Registered Leprosy Cases by Month (n=131)



Appendix 2

2004 U.S. Hansen's Disease Cases by Reporting State		
STATE	CASES	%
ARKANSAS	1	0.8%
CALIFORNIA	23	17.6%
CONNECTICUT	1	0.8%
FLORIDA	6	4.6%
GEORGIA	1	0.8%
HAWAII*	27	20.6%
INDIANA	1	0.8%
IOWA	1	0.8%
LOUISIANA	6	4.6%
MASSACHUSETTS	6	4.6%
MICHIGAN	1	0.8%
MINNESOTA	1	0.8%
MISSISSIPPI	2	1.5%
NEVADA	1	0.8%
NEW HAMPSHIRE	1	0.8%
NEW YORK	17	13.0%
OHIO	1	0.8%
OREGON	2	1.5%
PUERTO RICO	3	2.3%
TENNESSEE	1	0.8%
TEXAS	24	18.3%
UTAH	1	0.8%
WASHINGTON	2	1.5%
WEST VIRGINIA	1	0.8%
TOTAL	131	100.0%

*Includes 17 cases from 2003 reported in 2004

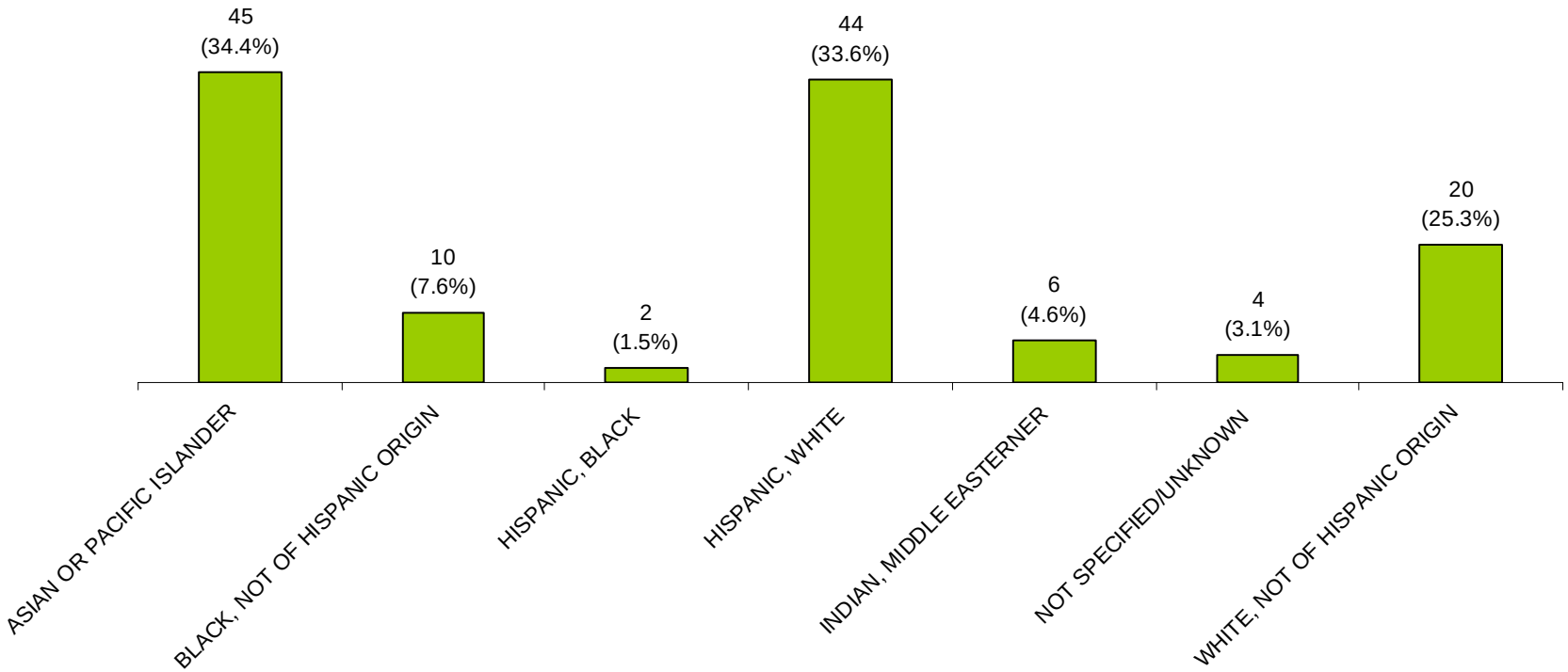


Appendix 3

2004 Reported Hansen's Disease Cases by Country of Birth		
COUNTRY	CASES	%
UNITED STATES	25	19.1%
MEXICO	24	18.3%
MICRONESIA	15	11.5%
BRAZIL	12	9.2%
PHILIPPINES	10	7.6%
TRUST TERRITORY	8	6.1%
INDIA	5	3.8%
CUBA	4	3.1%
VIETNAM	3	2.3%
PUERTO RICO	3	2.3%
NIGERIA	3	2.3%
LAOS	2	1.5%
GUYANA	2	1.5%
ECUADOR	2	1.5%
DOMINICAN REPUBLIC	2	1.5%
CHINA	2	1.5%
SURINAME	1	0.8%
SOMALIA	1	0.8%
PAKISTAN	1	0.8%
INDONESIA	1	0.8%
HAITI	1	0.8%
ETHIOPIA	1	0.8%
CAPE VERDE	1	0.8%
ARGENTINA	1	0.8%
AMERICAN SAMOA	1	0.8%
TOTAL	131	100.0%

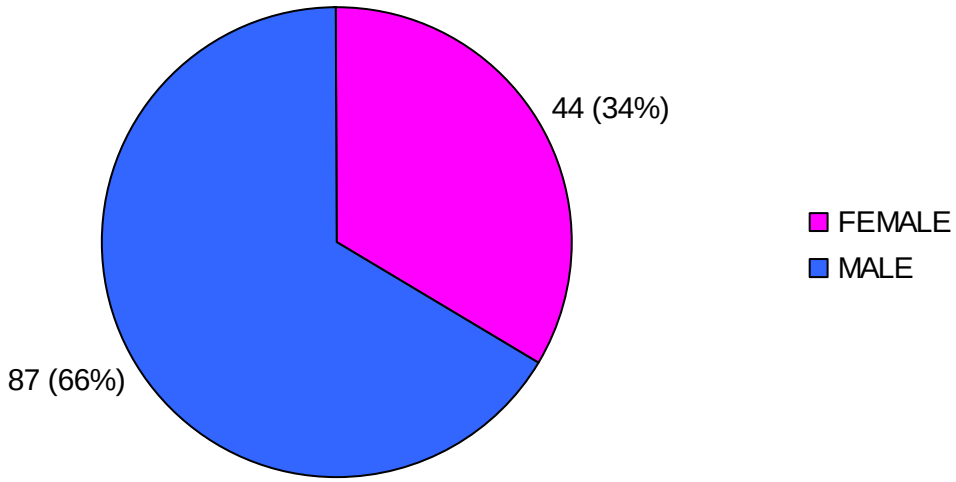
Appendix 4

2004 Registered Leprosy Cases by Race (n=131)



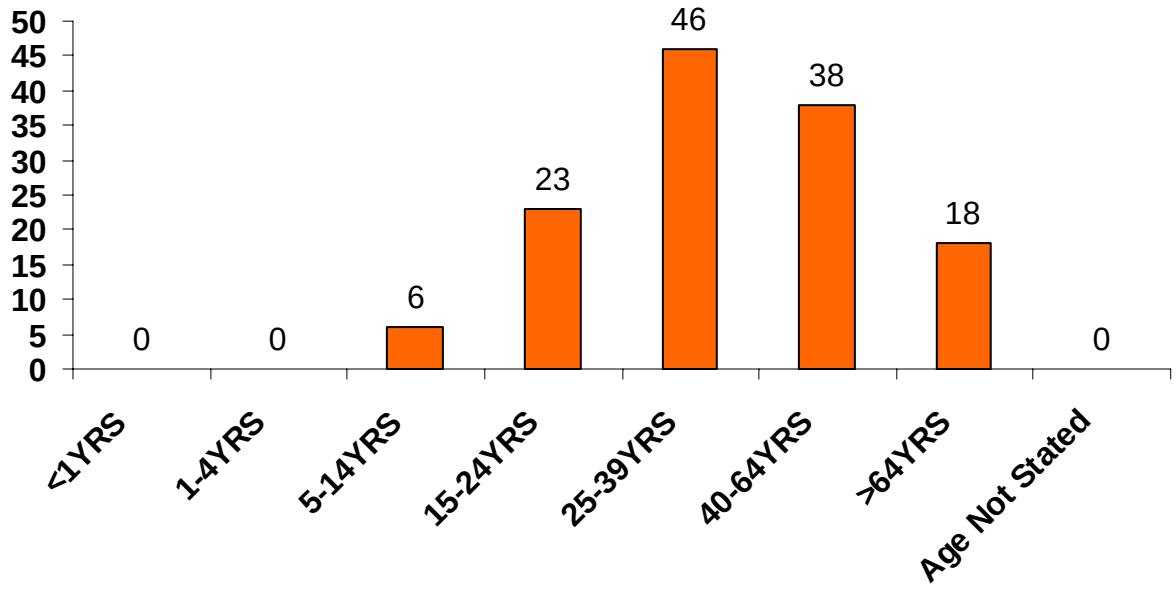
Appendix 5

2004 Registered Leprosy Patients by Gender (n=131)

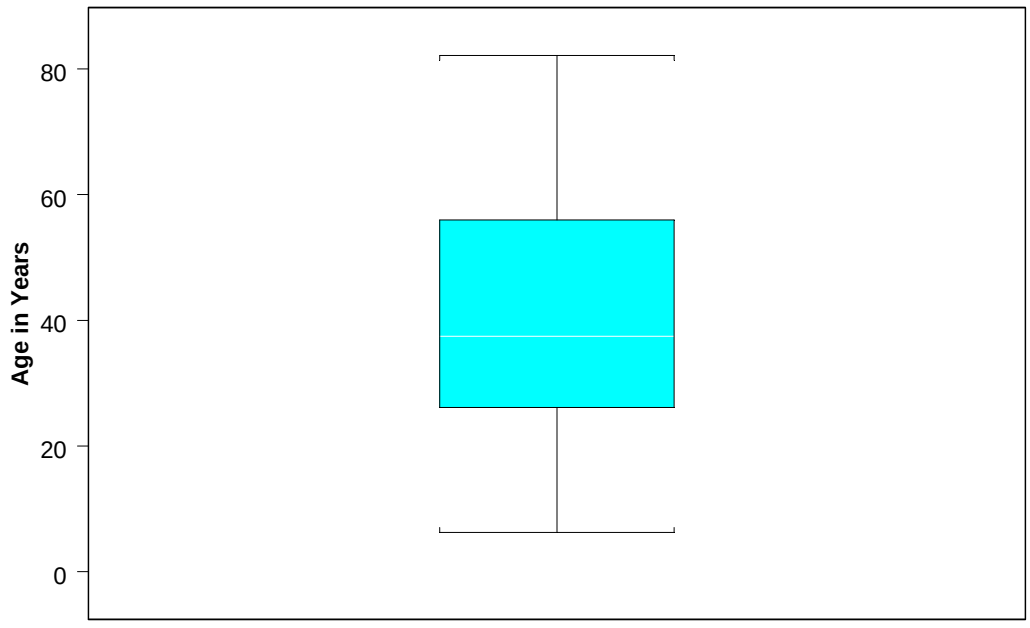


Appendix 6

2004 Registered Leprosy Cases by Age Group (n=131)



2004 Hansen's Disease Cases by Age at Diagnosis (n=131)

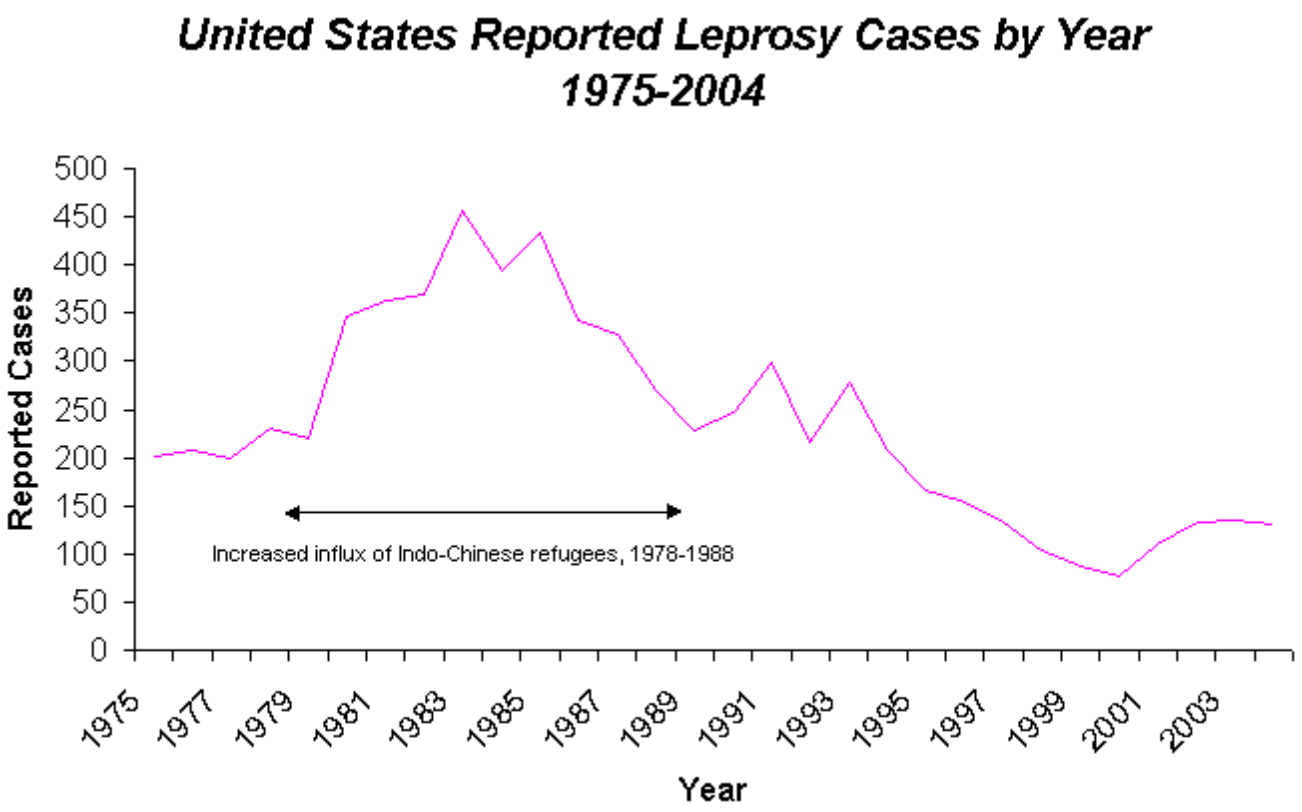


Appendix 7

2004 Hansen's Disease Cases by Ridley-Jopling Classification		
Borderline	24	40.0%
Borderline Lepromatous	5	8.3%
Borderline Tuberculoid	9	15.0%
Indeterminate	3	5.0%
Lepromatous Leprosy	14	23.3%
Tuberculoid	5	8.3%
TOTAL	60	100.0%

Appendix 8

YEAR	CASES
1975	201
1976	208
1977	200
1978	231
1979	220
1980	346
1981	363
1982	370
1983	456
1984	395
1985	434
1986	342
1987	327
1988	270
1989	229
1990	246
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	134
2004	131



In 2004, a total of 131 cases of Hansen's disease was reported in the United States.
The number of cases peaked at 456 in 1983, and since 1988 has remained relatively stable.