



A Summary of Hansen's Disease in the United States-2003

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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 is 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.

2003 Registry Summary

Temporal Distribution

In 2003 a total of 134 Hansen's disease cases were reported to the National Hansen's Disease Registry (NHDR), representing a 0.8% increase in the number of cases (n=133) reported in 2002. The monthly number of cases reported ranged from four (3.0%) in December to a maximum of 21 (15.7%) cases in April. Table 1 and the chart in Appendix 1 illustrate this monthly distribution.

<i>2003 Registered Leprosy Cases by Month</i>		
MONTH	CASES	PERCENT
JAN	15	11.2%
FEB	14	10.4%
MAR	17	12.7%
APR	21	15.7%
MAY	7	5.2%
JUN	9	6.7%
JUL	20	14.9%
AUG	7	5.2%
SEP	5	3.7%
OCT	9	6.7%
NOV	6	4.5%
DEC	4	3.0%
TOTAL	134	100.0%

Table 1

For the third straight year there was a disproportionate number of cases reported in the first seven months of the year. Compared to 2001 and 2002 in which 83% and 77% of the cases were respectively reported in the first seven months of the year, 77% (103) of the 2003 cases were reported in this same time period. 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 134 new cases reported to the registry in 2003, sixty-eight were newly diagnosed cases. Forty-eight (71%) were reported in the first seven months of the year. While an analysis of this temporal distribution of cases reported from 1894-2003 does not support this notion of seasonality, it is interesting that the distribution is so strikingly similar for the past three years. Since foreign born cases make up the majority of newly diagnosed and reported cases, these distributions may be explained by non-uniform immigration patterns. This non-uniform temporal distribution is certainly an area for further investigation.

Geographic Distribution of Cases

Leprosy cases were reported from 22 states in 2003. The table and corresponding density map in Appendix 2 depict HD cases reported in 2002 by state. Texas (27 cases, 20.1%), California (26, 19.4%), New York (15, 11.2%), Louisiana (12, 9.0%) and Florida (9, 6.7%) reported the most cases collectively representing two thirds (66.4%) of the cases. 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 134 reported cases, 108 (80.5%) were individuals born in 24 foreign countries. While the table in Appendix 3 shows the distribution by country of birth for the cases, the interpretation that most U.S. cases are being “imported” cannot be made unless consideration is given to the relationship between when these individuals entered the U.S. and when they were diagnosed. Of the 25 reported birth countries, the four countries of the United States, Mexico, India, and the Dominican Republic represent just over one-half (56.1%) of the reported cases in 2003.

There were 26 U.S. endemic cases born in 13 different states in 2003. Table 2 and the corresponding map illustrate the distribution of these cases by state of birth.

<i>2003 U.S. Native Born Leprosy Cases by State of Birth</i>	
LOUISIANA	9
TEXAS	6
ARIZONA	1
CALIFORNIA	1
COLORADO	1
FLORIDA	1
HAWAII	1
ILLINOIS	1
MISSISSIPPI	1
MISSOURI	1
NEW MEXICO	1
NEW YORK	1
UTAH	1
TOTAL	26

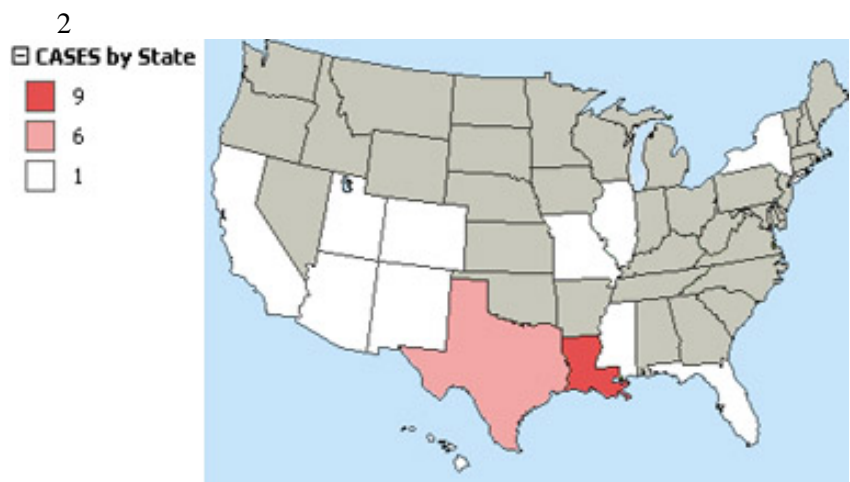


Table 2

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 2003 the cases listing the gulf coastal states of Louisiana, Texas, Florida, and Mississippi as the birth state represented 65% of the endemic cases. However, the bulk of these cases are attributed to Louisiana and Texas. As in 2002 where Texas and Louisiana together represented 56% of native-born leprosy cases, these two states alone accounted for 58% of such cases in 2003. 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 2003 reported cases by race and ethnicity. These data are also graphically represented in Appendix 4.

<i>2003 Reported Hansen’s Disease Cases by Race and Ethnicity</i>		
ASIAN OR PACIFIC ISLANDER	30	22.4%
BLACK, NOT OF HISPANIC ORIGIN	7	5.2%
HISPANIC, BLACK	11	8.2%
HISPANIC, WHITE	49	36.6%
INDIAN, MIDDLE EASTERNER	18	13.4%
WHITE, NOT OF HISPANIC ORIGIN	19	14.2%
TOTAL	134	100.0%

Table 3

As in 2001 and 2002 where they represented 31.8% and 35.3% of the respective cases, White Hispanics comprised the largest ethnic group increasing to 36.6% of the total cases. There also has been a rather marked increase in the proportion of the Indian, Middle Easterner category, rising from 7.3% in 2001 to 13.4% in 2003. The increases seen in these two groups correspond to decreases in the Asian or Pacific Islander and White, Not of Hispanic Origin groups for the same period. Given the facts that the vast majority of new cases are foreign born, and Mexico is the predominant country of birth for such cases, it is expected that the White Hispanic category will continue to represent the largest race and ethnicity segment of new cases for the foreseeable future. This distribution, however, can change dramatically if there are significant shifts in immigration patterns to other highly endemic countries.

Of the 134 cases reported to the registry in 2003, 96 (72%) were male and 38 (28%) were female (see Appendix 5). This roughly 3:1 ratio of males to females represents a shift from the 3:2 ratio (61% vs. 39%) seen in 2002. 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 in all U.S. cases reported through 2003 (1.7:1, n= 11,717).

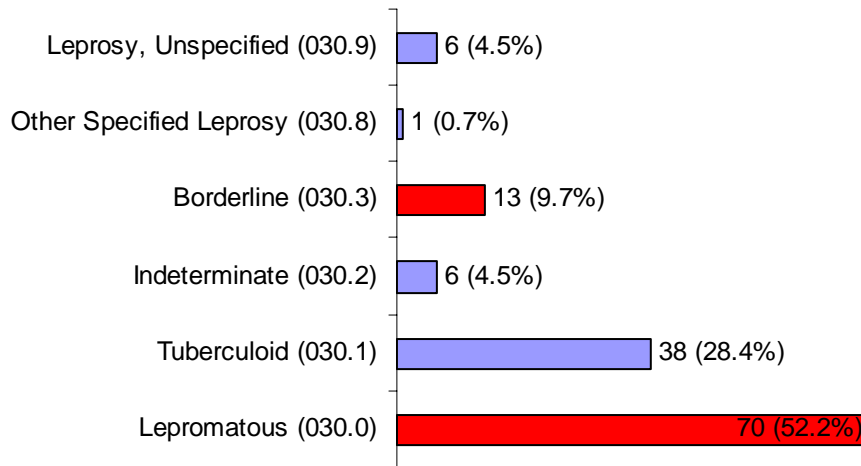
The age distribution of the sample is summarized by the graph and age at diagnosis boxplot in Appendix 7. For the cases reported to the registry in 2003 the age at diagnosis ranged from 3.8 to 87.6 years with a mean age of 40.4 ± 19.0 years. However, because Hansen’s disease is not prevalent in the very young, the median age of 33.6 years is a more reliable estimator of the middle of the distribution. This compares to median diagnosis ages of 37.6, 41.8, and 35.1 years for 2002, 2001, and all years through 2003 (n=10,427) respectively. The middle 50% of the 2003 cases have a diagnosis age between 25.7 and 53.7 years. Interestingly, for the 26 reported endemic cases in 2003, the median age at diagnosis was 51.5

years of age which was significantly different from the median age for foreign born cases (31.8 years, $p < 0.001$). The difference in the median age at diagnosis for the endemic cases might be attributed to race/ethnicity differences, since 73.1% of the 2003 endemic cases are classified as White, Non-Hispanic. Another possible explanation might be due to the possibility that individuals from other highly endemic countries may 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 2003 by disease type.

2003 Registered Leprosy Cases by ICD-9-CM Diagnosis Code (n=134)



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 2003, 83 (61.9%) and 51 (38.1%) of the reported cases are grouped as multibacillary and paucibacillary respectively. This approximate 6:4 ratio of multibacillary/paucibacillary classification represents a shift from the 7:3 ratio reported in 2002. The table in Appendix 7 provides the typing of these cases using the Ridley-Jopling classification.

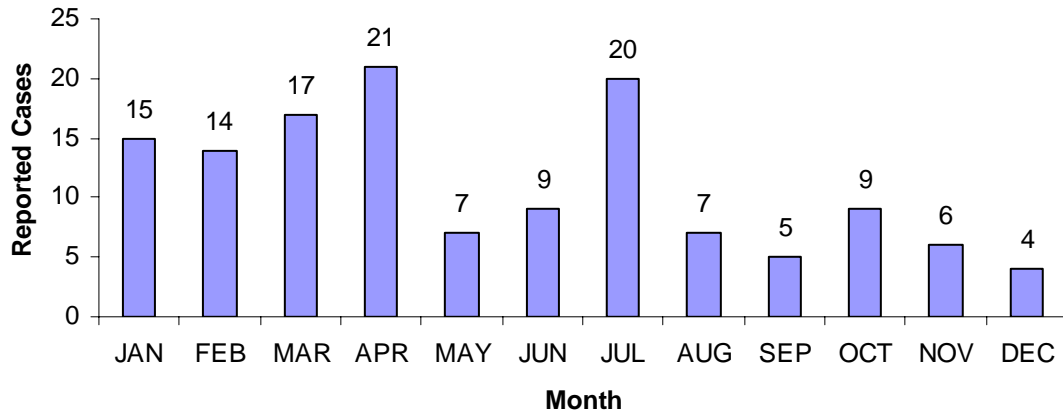
Historical Trend of Hansen’s Disease in the United States

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. In the past decade, the average number of new cases reported annually is 130.5. This decrease in reported U.S. cases since the early 1990’s is due to changes in immigration patterns, even though there has been 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 seen in this country is expected to be relatively constant in the future.

Appendix 1

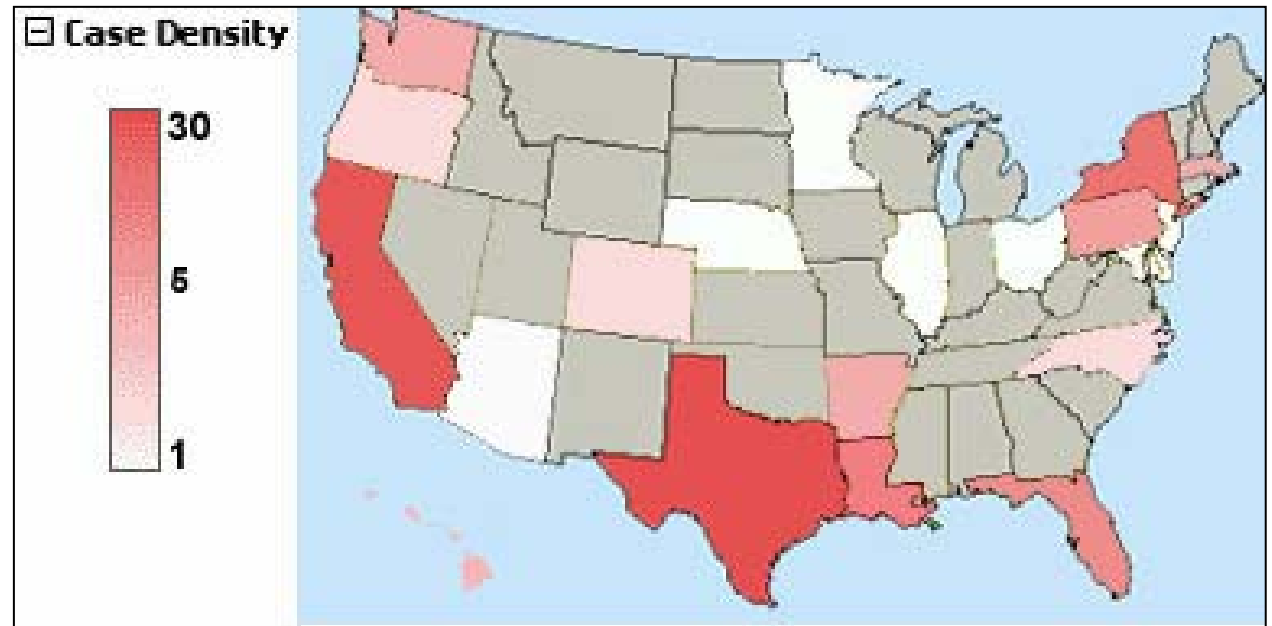
2003 Registered Leprosy Cases by Month
(n=134)



Appendix 2

2003 U.S. Hansen's Disease Cases by Reporting State

STATE	CASES	%
ARIZONA	1	0.7%
ARKANSAS	5	3.7%
CALIFORNIA	26	19.4%
COLORADO	2	1.5%
CONNECTICUT	1	0.7%
FLORIDA	9	6.7%
HAWAII	4	3.0%
ILLINOIS	1	0.7%
LOUISIANA	12	9.0%
MARYLAND	1	0.7%
MASSACHUSETTS	5	3.7%
MINNESOTA	1	0.7%
NEBRASKA	1	0.7%
NEW JERSEY	1	0.7%
NEW YORK	15	11.2%
NORTH CAROLINA	2	1.5%
OHIO	1	0.7%
OREGON	2	1.5%
PENNSYLVANIA	6	4.5%
PUERTO RICO	6	4.5%
TEXAS	27	20.1%
WASHINGTON	5	3.7%
TOTAL	134	100.0%



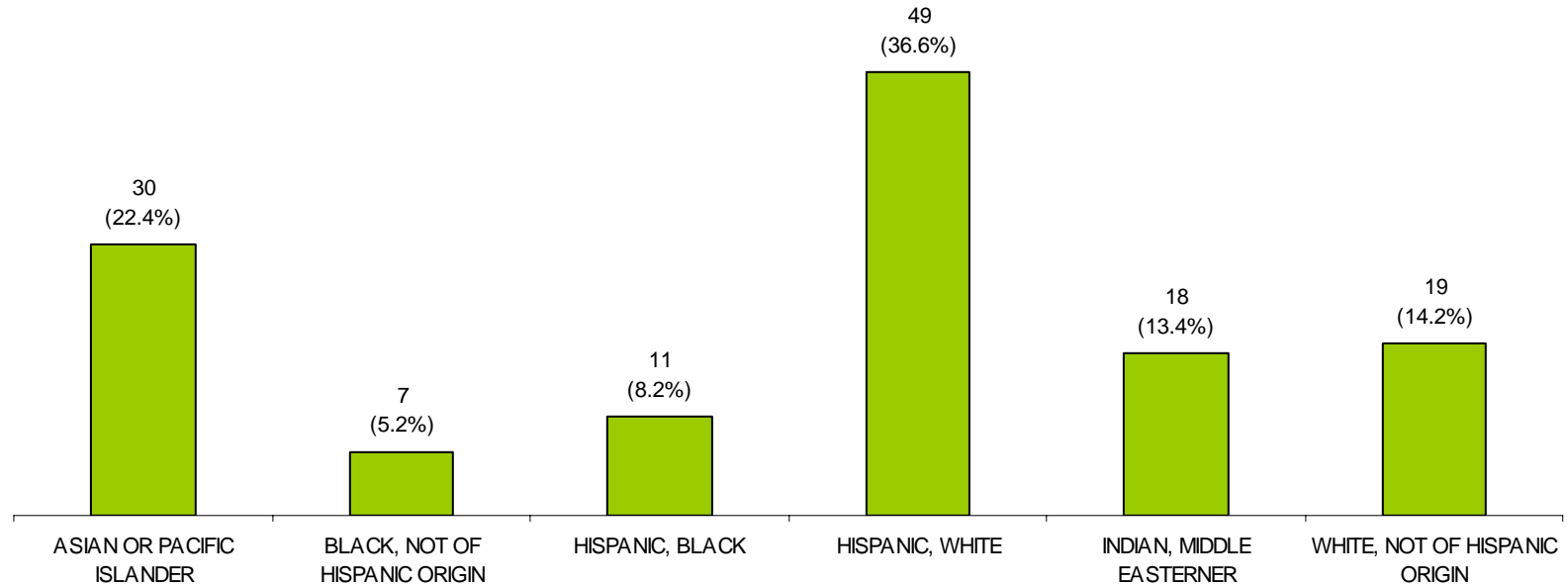
Appendix 3

2003 Reported Hansen's Disease Cases by Country of Birth

COUNTRY	CASES	%
UNITED STATES	26	19.4%
MEXICO	23	17.2%
INDIA	16	11.9%
DOMINICAN REPUBLIC	10	7.5%
BRAZIL	9	6.7%
PHILIPPINES	9	6.7%
CUBA	6	4.5%
TRUST TERRITORY	5	3.7%
PUERTO RICO	4	3.0%
INDONESIA	3	2.2%
LAOS	3	2.2%
TRINIDAD AND TOBAGO	3	2.2%
VIETNAM	3	2.2%
CHINA	2	1.5%
MICRONESIA	2	1.5%
BANGLADESH	1	0.7%
CHILE	1	0.7%
ECUADOR	1	0.7%
HAITI	1	0.7%
IRAN	1	0.7%
NIGERIA	1	0.7%
PARAGUAY	1	0.7%
SUDAN	1	0.7%
TAIWAN	1	0.7%
VENEZUELA	1	0.7%
TOTAL	134	100.0%

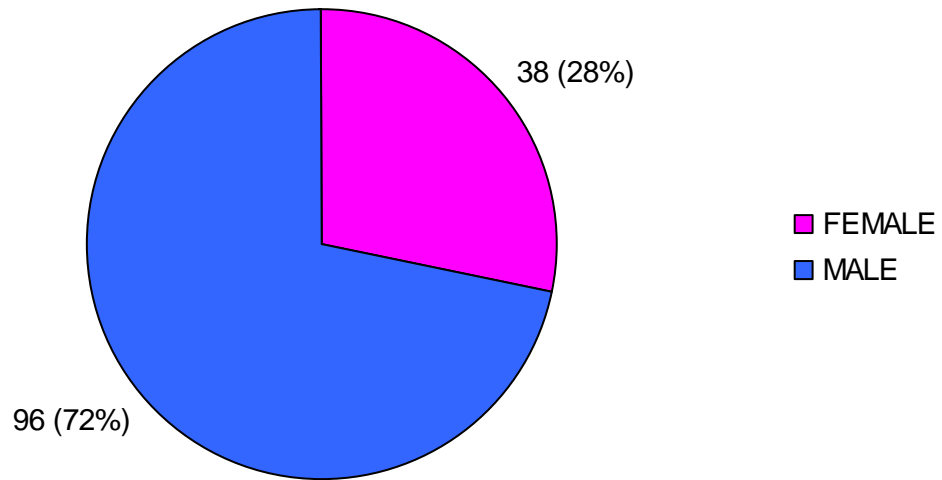
Appendix 4

2003 Registered Leprosy Cases by Race (n=134)



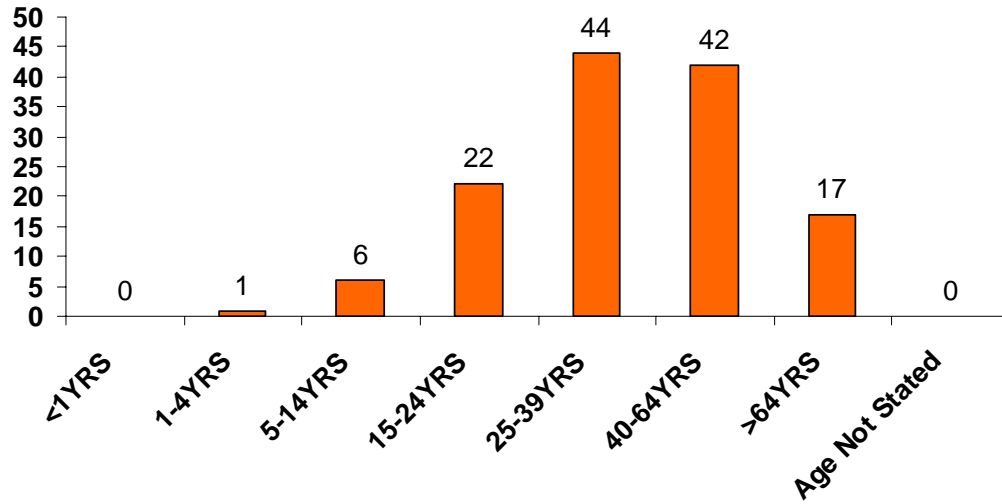
Appendix 5

2003 Registered Leprosy Patients by Gender (n=134)

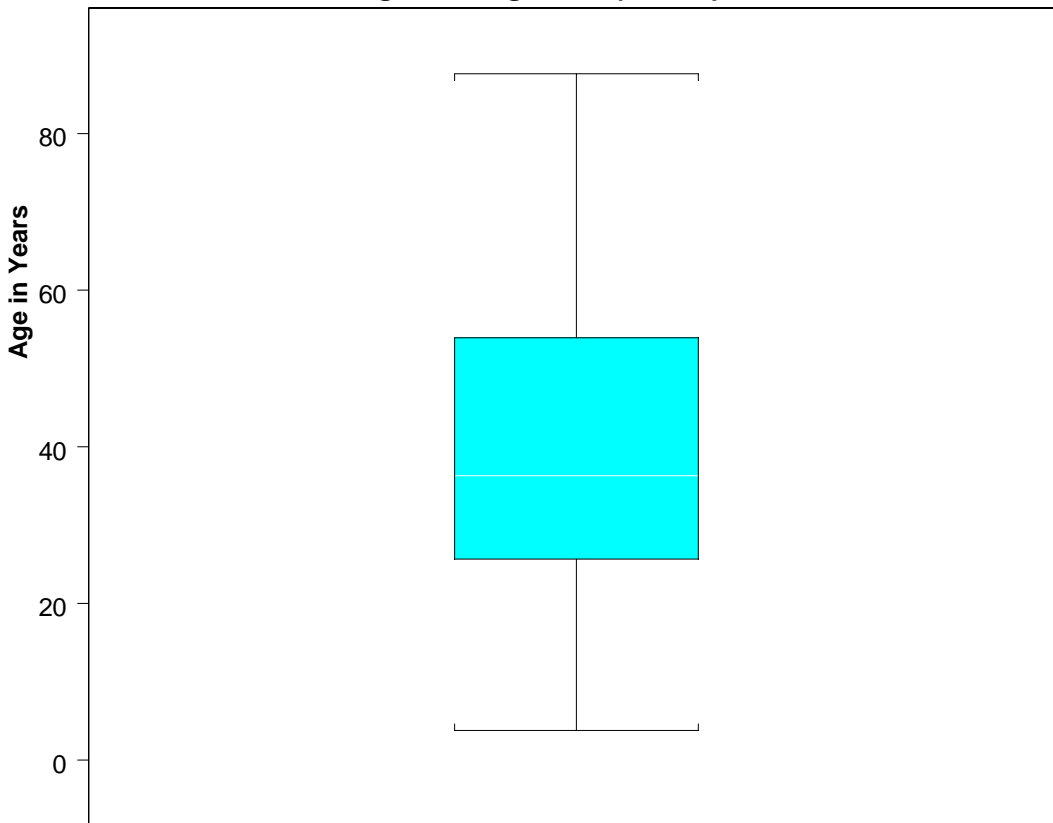


Appendix 6

**2003 Registered Leprosy Cases by Age Group
(n=134)**



**2003 Hansen's Disease Cases by
Age at Diagnosis (n=134)**

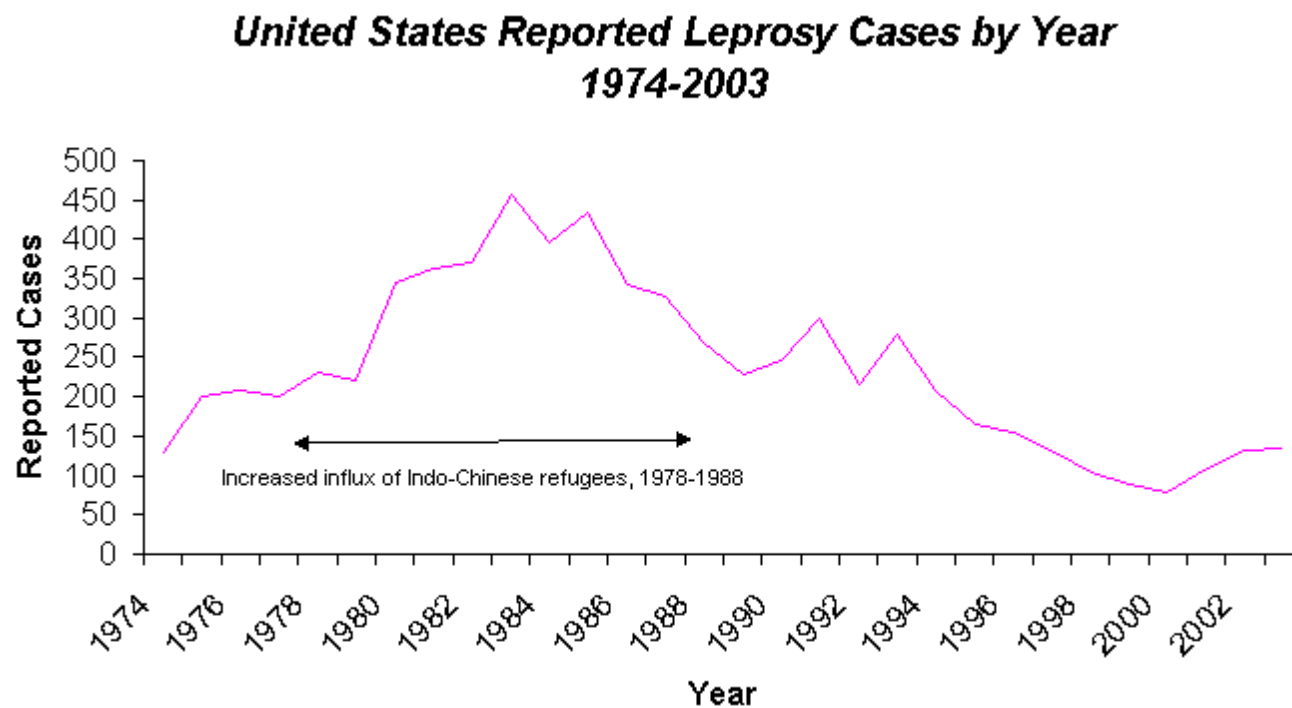


Appendix 7

<i>2003 Hansen's Disease Cases by Ridley-Jopling Classification</i>		
Borderline	7	9.2%
Borderline Lepromatous	11	14.5%
Borderline Tuberculoid	13	17.1%
Indeterminate	6	7.9%
Lepromatous Leprosy	33	43.4%
Tuberculoid	6	7.9%
TOTAL	76	100.0%

Appendix 8

YEAR	CASES
1973	186
1974	130
1975	201
1976	208
1977	200
1978	231
1979	220
1980	346
1981	363
1982	371
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	78
2001	110
2002	133
2003	134



In 2003, a total of 134 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.