



## A Summary of Hansen's Disease in the United States-2002

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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.

## 2002 Registry Summary

### ***Temporal Distribution***

In 2002 a total of 133 Hansen's disease cases were reported to the National Hansen's Disease Registry (NHDR), representing a 20.9% increase in the number of cases (n=110) reported in 2001. The monthly number of cases reported ranged from two (1.5%) in October to a maximum of 23 (17.3%) cases in March. Table 1 and the chart in Appendix 1 illustrate this monthly distribution.

<b><i>2002 Registered Leprosy Cases by Month</i></b>		
<b>MONTH</b>	<b>CASES</b>	<b>PERCENT</b>
JAN	17	12.8%
FEB	6	4.5%
MAR	23	17.3%
APR	16	12.0%
MAY	9	6.8%
JUN	11	8.3%
JUL	20	15.0%
AUG	10	7.5%
SEP	8	6.0%
OCT	2	1.5%
NOV	4	3.0%
DEC	7	5.3%
<b>TOTAL</b>	<b>133</b>	<b>100.00%</b>

Table 1

For the second straight year there were a disproportionate number of cases reported in the first seven months of the year. Compared to 2001 in which 83% of the cases were reported in the first seven months of the year, 77% of the 2002 cases were reported in this same time period. For the four month period of April-July, 52 (56%) and 56 (42%) cases were respectively reported in 2001 and 2002. Only 21 (16%) of the 2002 cases were reported in the last four months of the year. It is not known what circumstances may contribute to this non-uniform temporal distribution and is an area for further investigation.

### **Geographic Distribution of Cases**

As in 2001, leprosy cases were reported from 28 states in 2002. The table and corresponding density map in Appendix 2 depict HD cases reported in 2002 by state. At 42 cases, California reported almost three times the number of cases as did second place New York with 15 cases. Fully, almost one-third (31.6%) of the 2002 cases were reported from California. Texas, Hawaii, and Louisiana followed New York with 11, 10, and 8 cases respectively. These five states accounted for almost two-thirds (64.7%) of total cases reported. Other than Texas and Louisiana, which have a larger number of indigenous cases, the cases reported from these states are primarily a function of immigration patterns.

Approximately 81% (n=108) of the cases reported in 2002 were individuals who were born in 22 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 23 reported birth countries, the Mexico (24.1%), the United States (18.8%), and the Philippines (12.8%) represent just over one-half (55.7%) of the reported cases in 2002.

Looking at the 25 U.S. endemic cases reported in 2002, Table 2 and the corresponding map illustrate the distribution of these cases by state of birth.

<b>2002 U.S. Native Born Leprosy Cases by State of Birth</b>	
CALIFORNIA	3
HAWAII	1
LOUISIANA	6
MASSACHUSETTS	1
MINNESOTA	1
MISSISSIPPI	1
MISSOURI	1
NEW MEXICO	1
NEW YORK	1
TEXAS	8
VERMONT	1
TOTAL	25

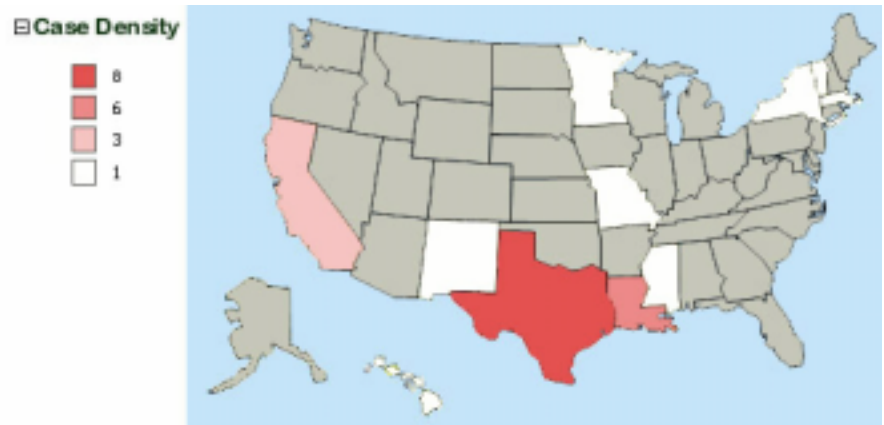


Table 2

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. Indeed, in 2002 Texas and Louisiana respectively represented 32% and 24% of native-born leprosy cases, with the combined gulf coastal cases from Louisiana, Texas and Mississippi accounting for 60% of endemic cases.

***Distribution of Cases by Race and Ethnicity, Age and Gender***

Table 3 summarizes the distribution of the 2002 reported cases by race and ethnicity. These data are also graphically represented in Appendix 4

<b><i>2002 Reported Hansen’s Disease Cases by Race and Ethnicity</i></b>		
AMERICAN INDIAN OR ALASKA NATIVE	1	0.8%
ASIAN OR PACIFIC ISLANDER	35	26.3%
BLACK, NOT OF HISPANIC ORIGIN	7	5.3%
HISPANIC, BLACK	6	4.5%
HISPANIC, WHITE	47	35.3%
INDIAN, MIDDLE EASTERNER	17	12.8%
NOT SPECIFIED/UNKNOWN	1	0.8%
WHITE, NOT OF HISPANIC ORIGIN	19	14.3%
TOTAL	133	100.0%

Table 3

Once again, White Hispanics comprised the largest ethnic group representing 35.3% of the total cases, and increasing from the 31.8% of the cases seen in 2001. The ethnic categories that followed are Asian or Pacific Islander (26.3%), White, Not of Hispanic Origin (14.3%), and Indian, Middle Easterner (12.8%). The four groups American Indian or Alaska Native; Black, Not of Hispanic Origin; Hispanic, Black; and Not Specified/Unknown made up the remaining 11.4% of the total cases. As with any race or ethnic classification exercise, these data are more subjective, because they rely on how individuals, and in some cases healthcare workers, perceive race and ethnicity.

Of the 133 cases reported to the registry in 2002, 81 (61%) were male and 52 (39%) were female (see Appendix 5). The age distribution of the sample is summarized in Table 4 and Appendix 7. Age was computed as the age at initial diagnosis.

<b><i>2002 Reported Leprosy Cases Age Distribution Summary</i></b>	
MEAN	41.4
STDEV	17.9
MEDIAN	37.6
MINIMUM	13.5
MAXIMUM	85.0
MODE	22.7

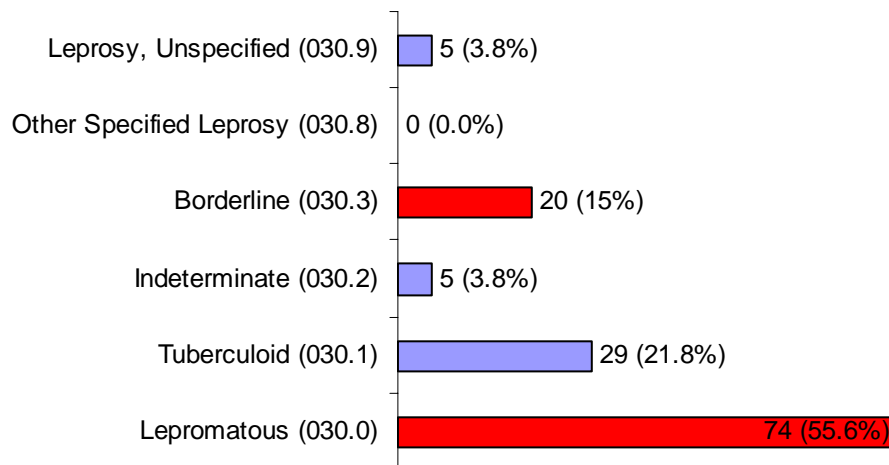
Table 4

The age at diagnosis for the cases reported to the registry in 2002 ranged from 13.5 to 85.0 years with a median age of 37.6 years. This compared to a range of 7.1 to 88.2 years and a median age of 41.8 years reported in 2001. This age distribution is graphically depicted by the boxplot in Appendix 6 which shows the median, upper and lower quartiles and extent of the data beyond the quartiles. While Hansen’s disease is predominately diagnosed in older individuals with approximately 50% of the cases reported in individuals between the ages of 30-50 years, the disease is seen in all age groups with the exception of the very young. Some areas for further investigation would be age within gender, race and ethnicity, and severity of the disease (disease classification).

**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 2001 by disease type.

**2002 Registered Leprosy Cases by ICD-9-CM Diagnosis Code (n=133)**



A category of multibacillary cases can be created by combining the borderline and lepromatous classes. Likewise, paucibacillary cases can be identified by grouping tuberculoid and indeterminate categories. For 2002, 94 (70.7%) and 39 (29.3%) 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.

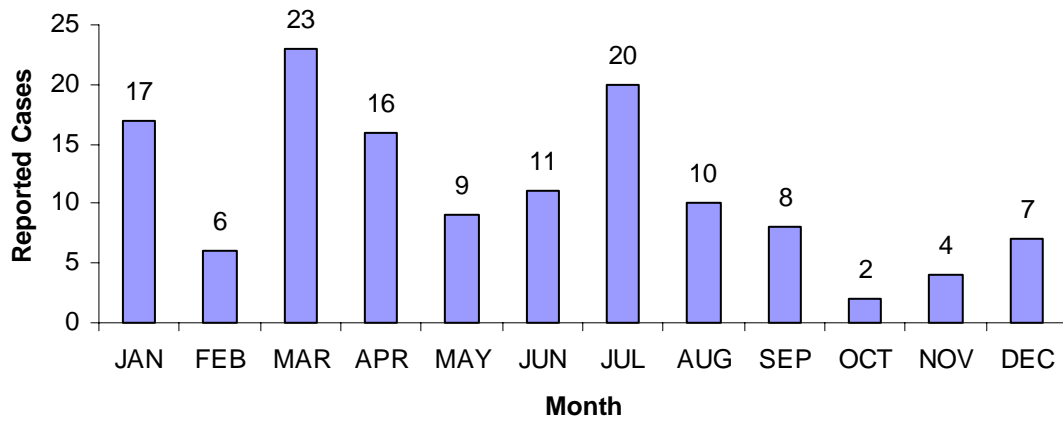
**Historical Trend of Hansen’s Disease in the United States**

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 150-200 new cases each year. In the past decade, the number of new cases has fluctuated between 120 and 150. This decrease in reported cases since the early 1990’s most likely

reflects the decline in leprosy 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.

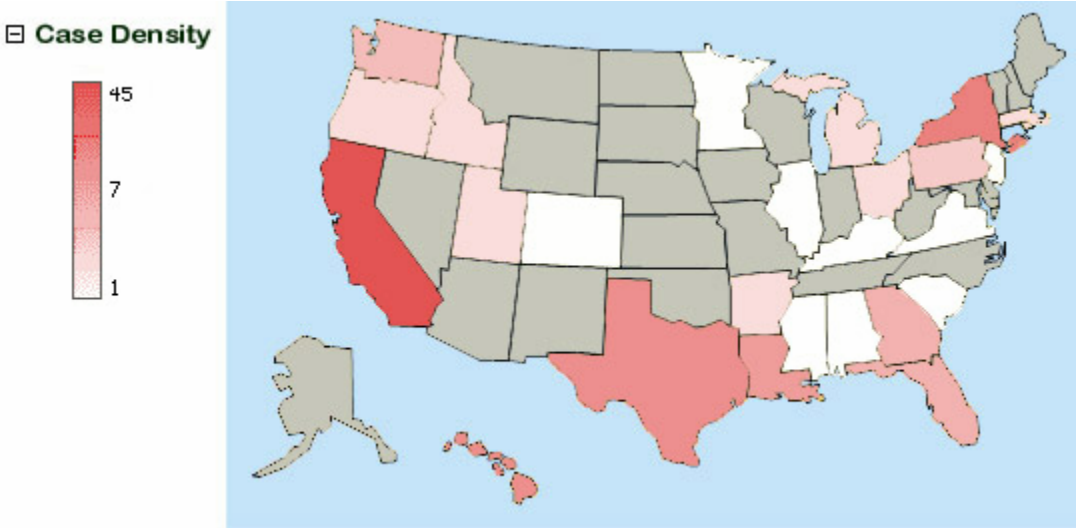
# Appendix 1

*2002 Registered Leprosy Cases by Month*  
(n=133)



## Appendix 2

<i>2002 U.S. Hansen's Disease Cases by Reporting State</i>		
STATE	CASES	%
ALABAMA	1	0.8%
ARKANSAS	2	1.5%
CALIFORNIA	42	31.6%
COLORADO	1	0.8%
CONNECTICUT	1	0.8%
DISTRICT OF COLUMBIA	1	0.8%
FLORIDA	7	5.3%
GEORGIA	5	3.8%
HAWAII	10	7.5%
IDAHO	3	2.3%
ILLINOIS	1	0.8%
KENTUCKY	1	0.8%
LOUISIANA	8	6.0%
MASSACHUSETTS	2	1.5%
MICHIGAN	2	1.5%
MINNESOTA	1	0.8%
MISSISSIPPI	1	0.8%
NEW JERSEY	1	0.8%
NEW YORK	15	11.3%
OHIO	2	1.5%
OREGON	2	1.5%
PENNSYLVANIA	3	2.3%
PUERTO RICO	2	1.5%
SOUTH CAROLINA	1	0.8%
TEXAS	11	8.3%
UTAH	2	1.5%
VIRGINIA	1	0.8%
WASHINGTON	4	3.0%
TOTAL	133	100.0%



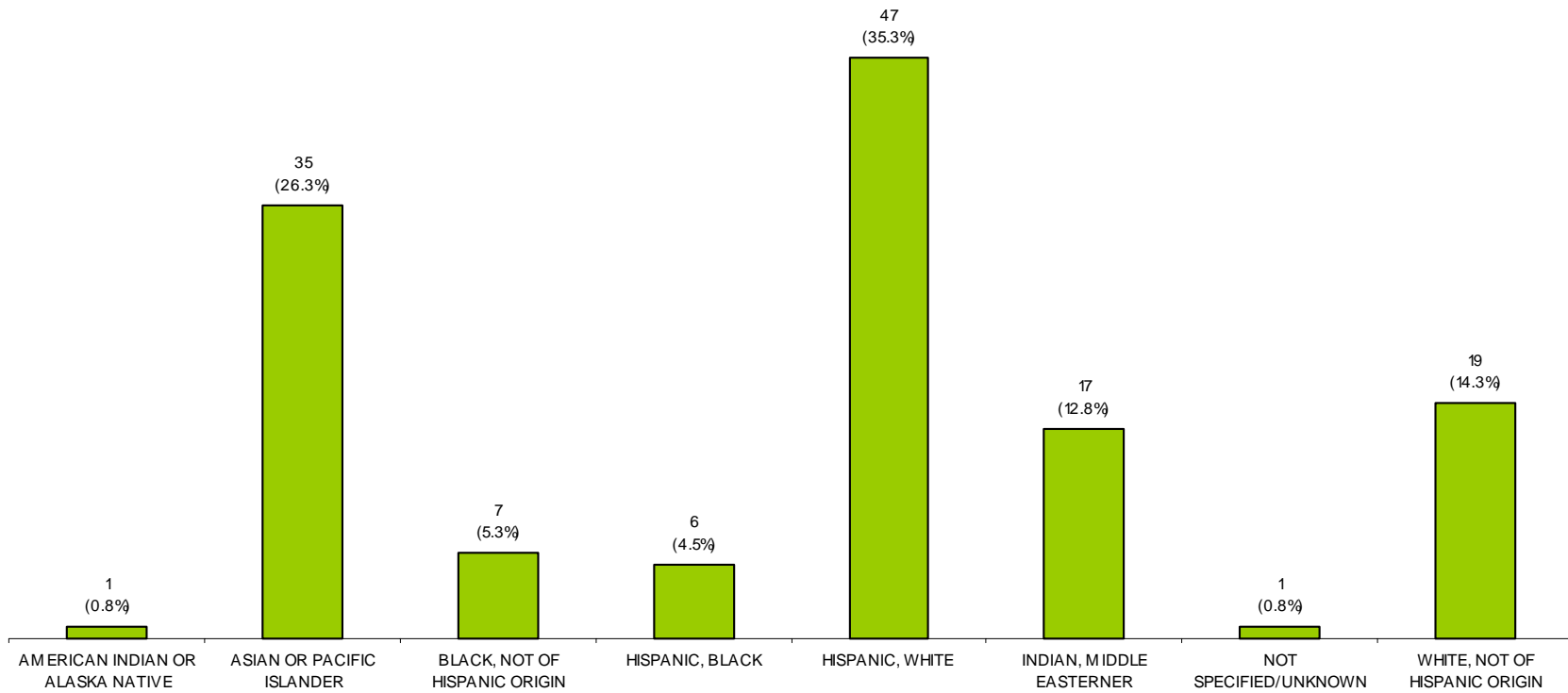


### Appendix 3

<i>2002 Reported Hansen's Disease Cases by Country of Birth</i>		
COUNTRY	CASES	%
AMERICAN SAMOA	1	0.8%
BANGLADESH	1	0.8%
BRAZIL	7	5.3%
COSTA RICA	1	0.8%
CUBA	2	1.5%
DOMINICAN REPUBLIC	3	2.3%
ECUADOR	1	0.8%
GUYANA	1	0.8%
INDIA	13	9.8%
JORDAN	1	0.8%
LEBANON	1	0.8%
MEXICO	32	24.1%
MICRONESIA	7	5.3%
NIGERIA	1	0.8%
PAKISTAN	2	1.5%
PHILIPPINES	17	12.8%
PUERTO RICO	4	3.0%
SOMALIA	1	0.8%
ST CHRISTOPHER NEVIS ST KITTS	1	0.8%
TRINIDAD AND TOBAGO	1	0.8%
TRUST TERRITORY	4	3.0%
UNITED STATES	25	18.8%
UNKNOWN	2	1.5%
VIETNAM	4	3.0%
TOTAL	133	100.0%

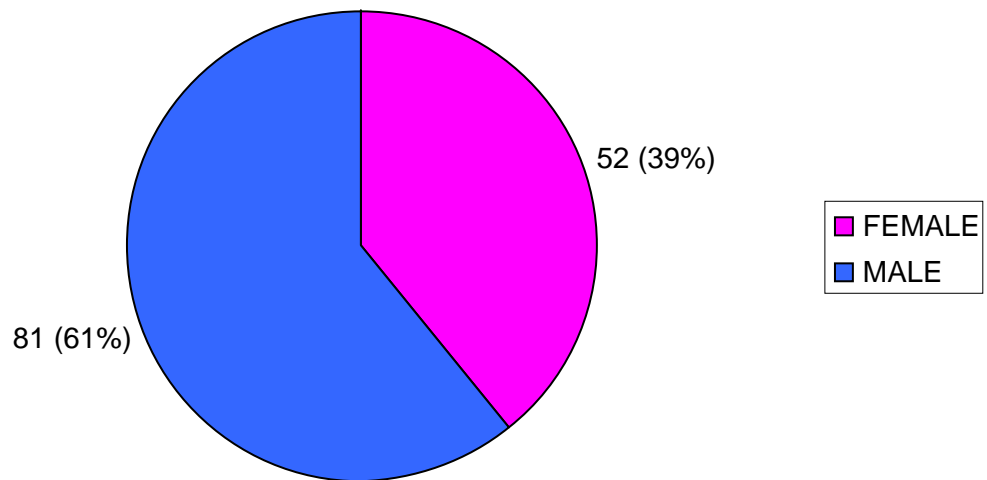
## Appendix 4

### *2002 Registered Leprosy Cases by Race (n=133)*



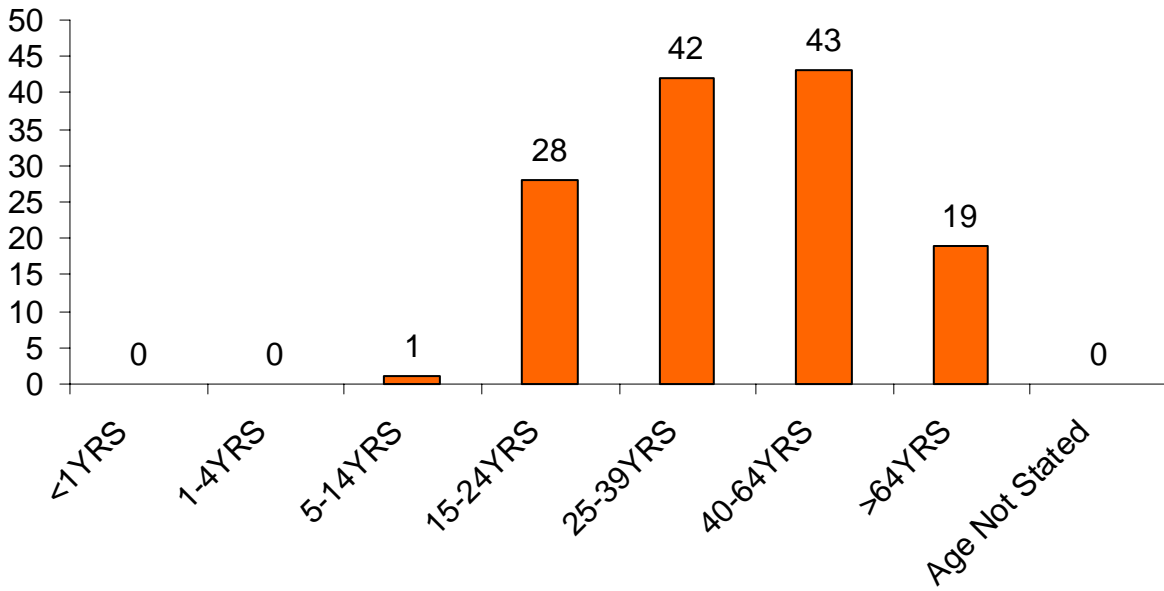
## Appendix 5

### *2002 Registered Leprosy Patients by Gender (n=133)*

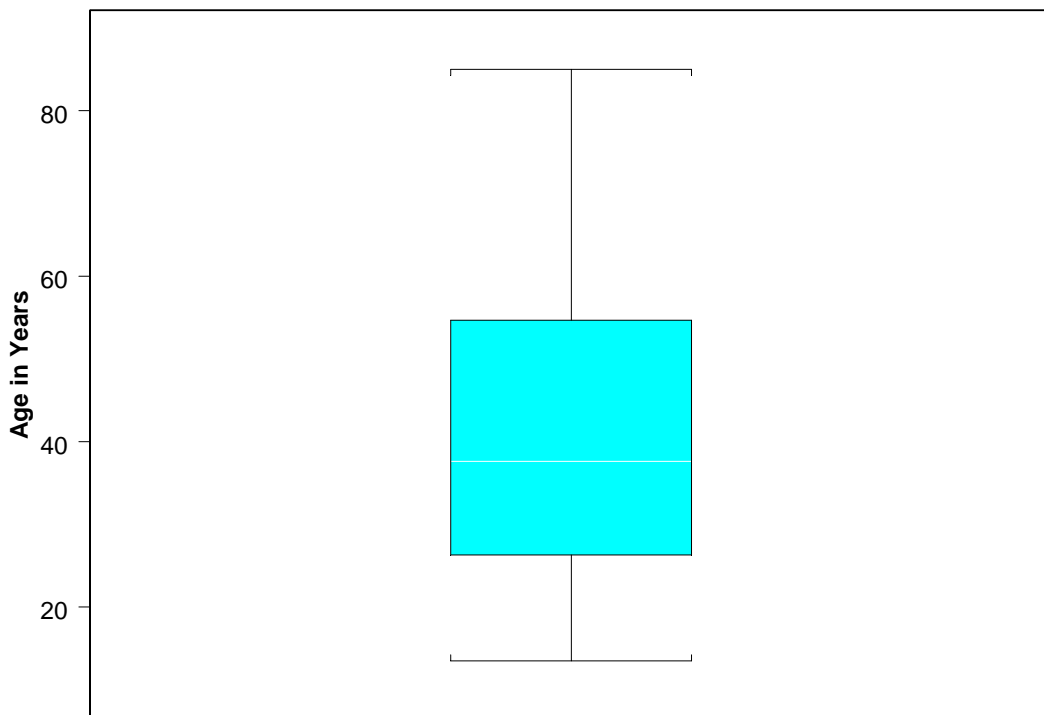


## Appendix 6

### 2002 Registered Leprosy Cases by Age Group (n=133)



### 2002 Reported Hansen's Disease by Age at Diagnosis



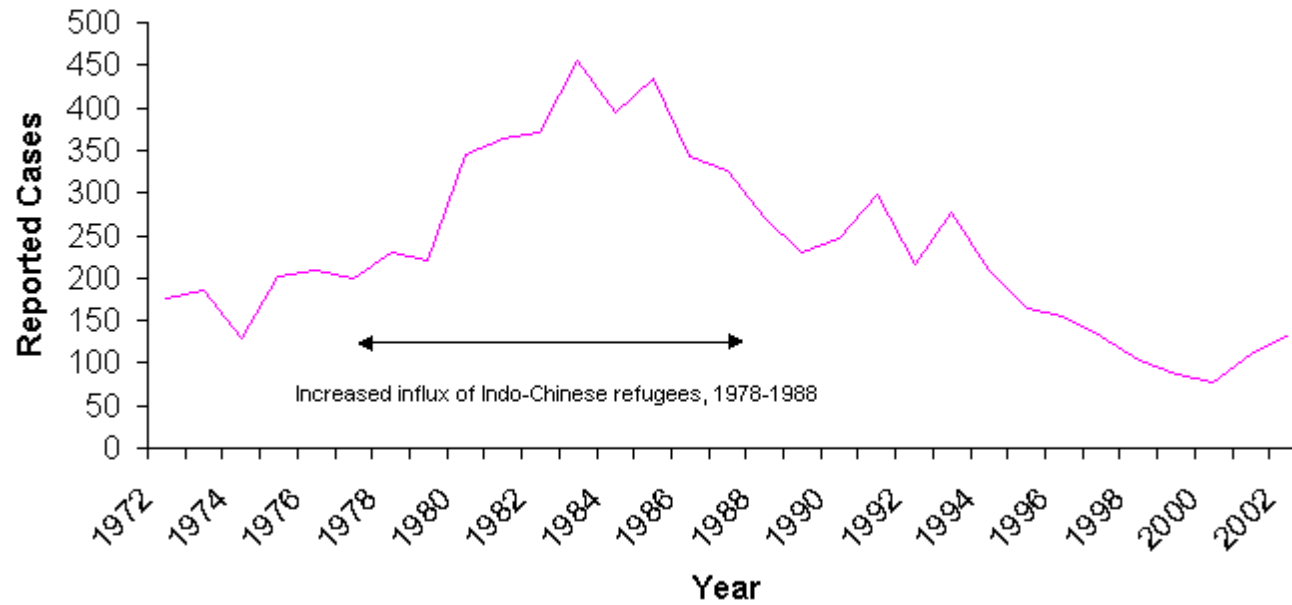
## Appendix 7

<i>2002 Hansen's Disease Cases by Ridley-Jopling Classification</i>		
Borderline	15	15.6%
Borderline Lepromatous	13	13.5%
Borderline Tuberculoid	12	12.5%
Indeterminate	4	4.2%
Lepromatous Leprosy	42	43.8%
Tuberculoid	10	10.4%
TOTAL	96	100.0%

## Appendix 8

YEAR	CASES
1972	177
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

**United States Reported Leprosy Cases by Year, 1972-2002**



In 2002, a total of 133 cases of Hansen's disease were reported in the United States. The number of cases peaked at 456 in 1983, and since 1988 has remained relatively stable.