



## A Summary of Hansen's Disease in the United States-2001

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## Introduction

The National Hansen's Disease Program (NHDP) has a mission 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 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 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.

## 2001 Registry Summary

### ***Temporal Distribution***

In 2001 a total of 110 Hansen's disease cases were reported to the National Hansen's Disease Registry (NHDR). The monthly number of cases reported ranged from zero in December to a maximum of 19 (17.3%) cases in June. Table 1 and the chart in Appendix 1 illustrate this monthly distribution.

<b><i>2001 Registered Leprosy Cases by Month</i></b>		
<b>MONTH</b>	<b>CASES</b>	<b>PERCENT</b>
JAN	13	11.8%
FEB	7	6.4%
MAR	9	8.2%
APR	16	14.5%
MAY	12	10.9%
JUN	19	17.3%
JUL	15	13.6%
AUG	6	5.5%
SEP	4	3.6%
OCT	8	7.3%
NOV	1	0.9%
DEC	0	0.0%
<b>TOTAL</b>	<b>110</b>	<b>100.0%</b>

Table 1

It is interesting to note that this temporal distribution is by no means uniform. Approximately 83% of the cases were reported in the first seven months of the year with 52 cases (56.3%) reported in the four month period of April-July, 2001. 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**

Leprosy cases were reported from 28 states and Puerto Rico in 2001. The table and corresponding density map in Appendix 2 depict HD cases reported in 2001 by state. Texas and New York tied for the most cases at 16 each. They were followed by Louisiana (15), Washington (11), and Florida and California at 10 cases each. These six states accounted for 70.9% of total number of leprosy 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 73% of the cases reported in 2001 were individuals who were born in a foreign country and have entered the U.S. 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 24 reported birth countries, the United States (27.3%), Mexico (18.2%), India (9.1%), and the Philippines (8.2%) represent almost two-thirds (62.8%) of the reported cases in 2001.

Looking at the 30 U.S. endemic cases reported in 2001, Table 2 and the corresponding map illustrate the distribution of these cases by state of birth (including Puerto Rico). These graphics also can be found in Appendix 4.

<i>2001 U.S. Native Born Leprosy Cases by State of Birth</i>	
ALABAMA	1
PUERTO RICO	1
LOUISIANA	13
MAINE	1
MICHIGAN	1
MISSISSIPPI	2
MISSOURI	1
OKLAHOMA	2
TEXAS	8
TOTAL	30



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 2001 Louisiana alone represented 43.3% of native-born leprosy cases followed by Texas with 26.6%. Collectively, the gulf coastal states of Louisiana, Texas and Mississippi represent 76.7% of endemic U.S. cases in 2001.

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

Table 3 summarizes the distribution of the 2001 reported cases by race and ethnicity. These data are also graphically represented in Appendix 5.

<b>2001 Reported Hansen's Disease Cases by Race and Ethnicity</b>		
AMERICAN INDIAN OR ALASKA NATIVE	1	0.9%
ASIAN OR PACIFIC ISLANDER	25	22.7%
BLACK, NOT OF HISPANIC ORIGIN	8	7.3%
HISPANIC, BLACK	7	6.4%
HISPANIC, WHITE	35	31.8%
INDIAN, MIDDLE EASTERNER	8	7.3%
NOT SPECIFIED/UNKNOWN	5	4.5%
WHITE, NOT OF HISPANIC ORIGIN	21	19.1%
TOTAL	110	100.0%

Table 3

White Hispanics comprised the largest ethnic group representing 31.8% of the total cases. This group was followed by Asian or Pacific Islander (22.7%) and White, Not of Hispanic Origin (19.1%). The group Indian, Middle Easterner was newly added to the revised surveillance form at the end of the calendar year 2000. This group was added to prevent confusion in collecting and processing surveillance information, and subdivide major populations with a substantial number of leprosy cases on the Asian continent. Since the new surveillance form was not fully implemented during 2001, the Indian, Middle Easterner ethnic group is probably underrepresented, and intersects to some degree with the Asian or Pacific Islander group. Comparisons of these groups then, with data from previous years, must take this new categorization into consideration. As with any 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 110 cases reported to the registry in 2001, 70 (64%) were male and 40 (36%) were female (see Appendix 6). The age distribution of the sample is summarized in Table 4 and Appendix 7. Age was computed as the age at initial diagnosis, and not age at reporting which is of less interest.

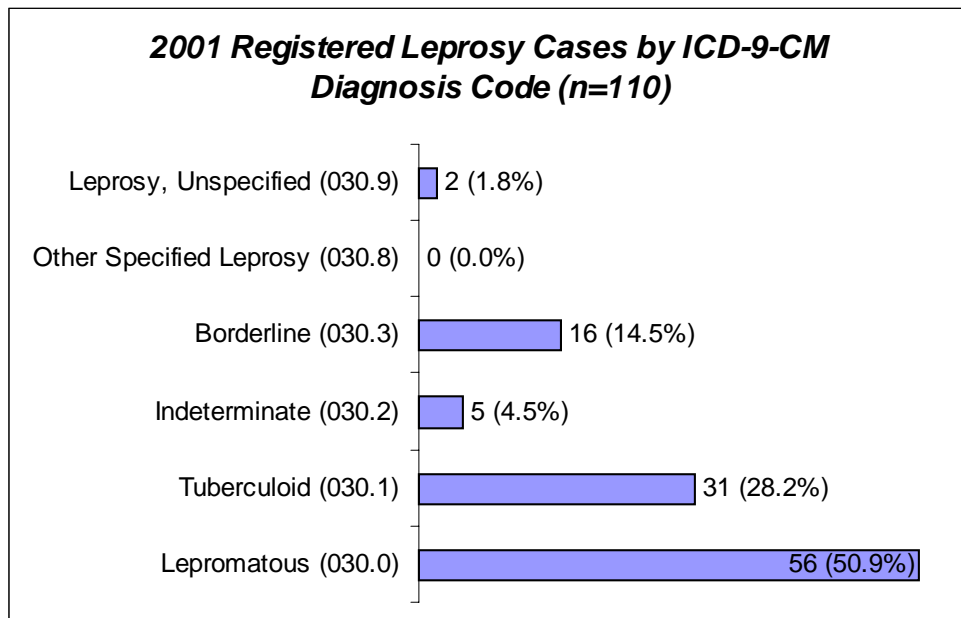
<b>2001 Reported Leprosy Cases Age Distribution Summary</b>	
MEAN	43.0
MINIMUM	7.1
MAXIMUM	88.2
STDEV	17.5
MODE	40.6
MEDIAN	41.8
COUNT	109

Table 4

The age at diagnosis for the cases reported to the registry in 2001 ranged from 7.1 to 88.2 years with a median age of 41.8 years. This age distribution is graphically depicted by the boxplot in Appendix 7 which shows the median, upper and lower quartiles and extent of the data beyond the quartiles. Because the upper and lower quartiles are approximately equidistant from the median, the distribution is judged to be approximately symmetric in the middle. However, the age at diagnosis extends considerably beyond the middle in both directions. These data suggest that the disease is not highly associated with age and, with the exception of the very young, is fairly evenly distributed across the age spectrum. 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 revised 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). This classification scheme is often considered an indicator of disease severity. The following chart quantifies the cases reported to the registry in 2001 by disease type.



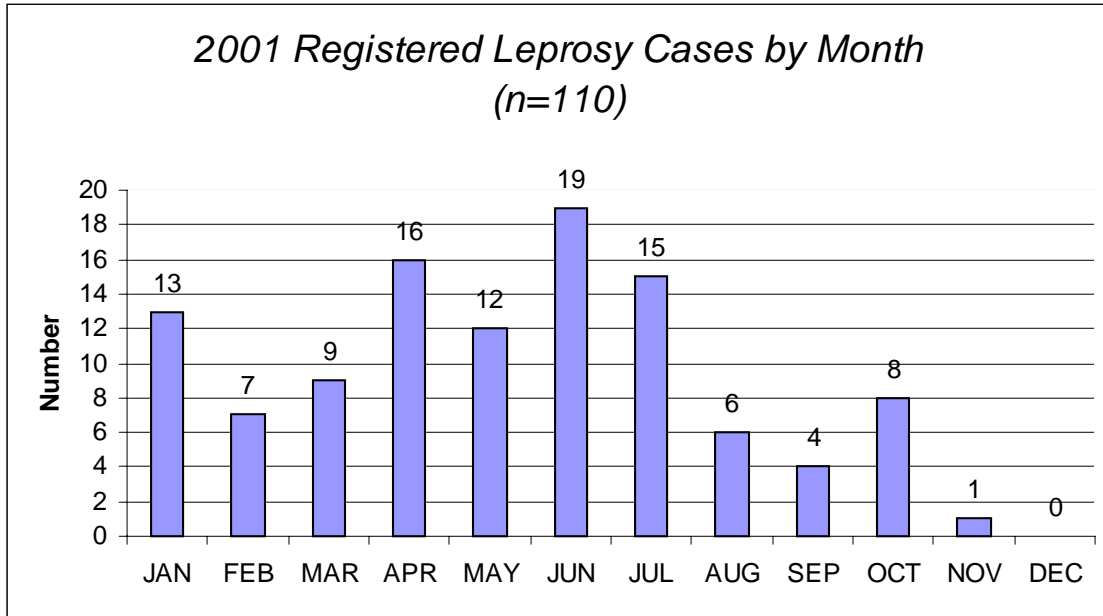
A category of multibacillary cases can be created by combining the borderline and lepromatous classes. Likewise, paucibacillary cases can be identified by grouping tuberculoid and indeterminate categories. For 2001, 72 (65.4%) and 36 (32.7%) of the reported cases are grouped as multibacillary and paucibacillary respectively. Although it is less important from a clinical and epidemiological standpoint, the table in Appendix 8 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 9 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 100-200 new case each year. Because the number of endemic cases is stable at

approximately 30 new cases a year, fluctuations in reported cases is primarily a function of immigration patterns. Areas for future investigation include quantifying the number of cases with a diagnosis before entry into the U.S., and examining the temporal relationship between time of entry and diagnosis for those cases that are diagnosed after entry.

## Appendix 1



## Appendix 2

<i>2001 U.S. Hansen's Disease Cases by Reporting State</i>		
STATE	CASES	%
ARKANSAS	1	0.9%
CALIFORNIA	10	9.1%
COLORADO	1	0.9%
FLORIDA	10	9.1%
GEORGIA	2	1.8%
HAWAII	1	0.9%
ILLINOIS	3	2.7%
INDIANA	1	0.9%
IOWA	4	3.6%
KANSAS	1	0.9%
LOUISIANA	15	13.6%
MARYLAND	1	0.9%
MISSISSIPPI	2	1.8%
NEBRASKA	1	0.9%
NEVADA	1	0.9%
NEW JERSEY	1	0.9%
NEW YORK	16	14.5%
OHIO	1	0.9%
OKLAHOMA	1	0.9%
OREGON	4	3.6%
PENNSYLVANIA	1	0.9%
PUERTO RICO	1	0.9%
TENNESSEE	1	0.9%
TEXAS	16	14.5%
UTAH	1	0.9%
VIRGINIA	1	0.9%
WASHINGTON	11	10.0%
WISCONSIN	1	0.9%
	110	100.0%





### Appendix 3

#### *2001 Reported Hansen's Disease Cases by Country of Birth*

COUNTRY	CASES	%
AMERICAN SAMOA	2	1.8%
BRAZIL	5	4.5%
BURMA	2	1.8%
COLOMBIA	1	0.9%
COSTA RICA	1	0.9%
CUBA	4	3.6%
DOMINICAN REPUBLIC	6	5.5%
EL SALVADOR	1	0.9%
GAMBIA	1	0.9%
GUYANA	1	0.9%
HAITI	2	1.8%
INDIA	10	9.1%
MEXICO	20	18.2%
MICRONESIA	5	4.5%
PAKISTAN	1	0.9%
PHILIPPINES	9	8.2%
SENEGAL	1	0.9%
SOLOMON ISLANDS	1	0.9%
SRI LANKA	2	1.8%
SUDAN	2	1.8%
TRINIDAD AND TOBAGO	1	0.9%
TRUST TERRITORY	1	0.9%
UNITED STATES	30	27.3%
VIETNAM	1	0.9%
TOTAL	110	100.0%

### Appendix 4

<i>2001 U.S. Native Born Leprosy Cases by State of Birth</i>	
ALABAMA	1
PUERTO RICO	1
LOUISIANA	13
MAINE	1
MICHIGAN	1
MISSISSIPPI	2
MISSOURI	1
OKLAHOMA	2
TEXAS	8
TOTAL	30

☐ Density of Endemic Cases

■ 13

■ 8

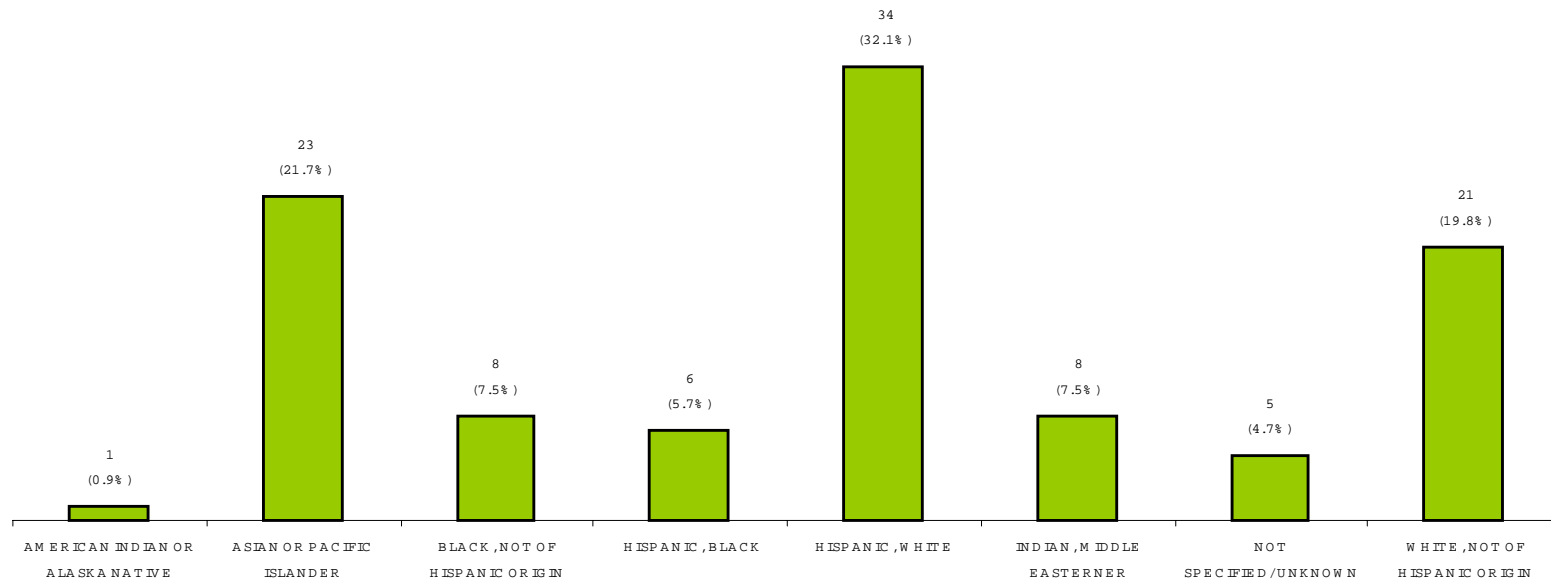
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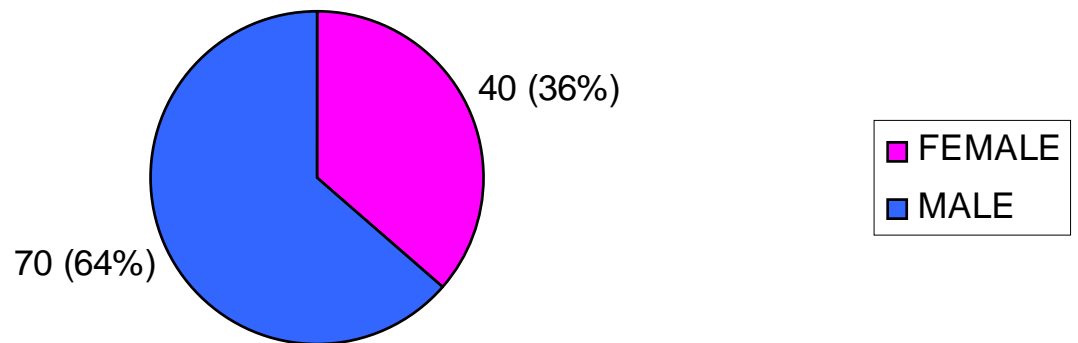
## Appendix 5

### 2001 Registered Leprosy Cases by Race (n=110)

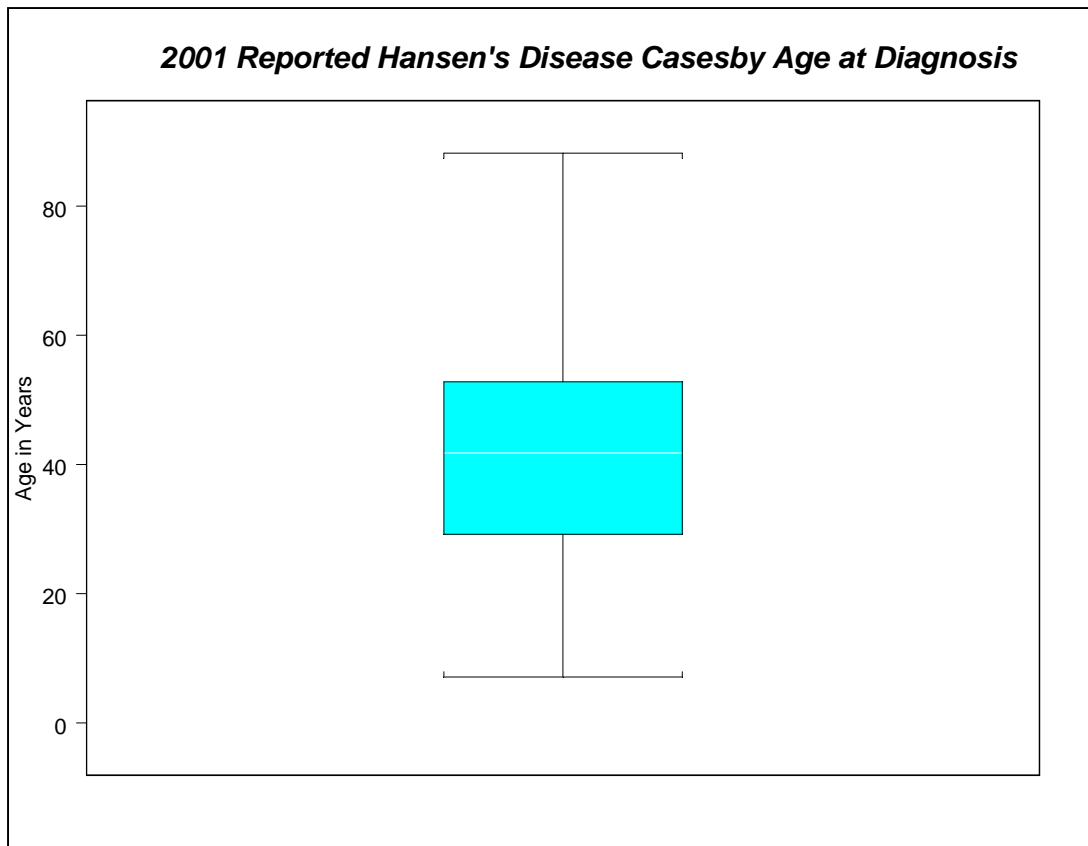
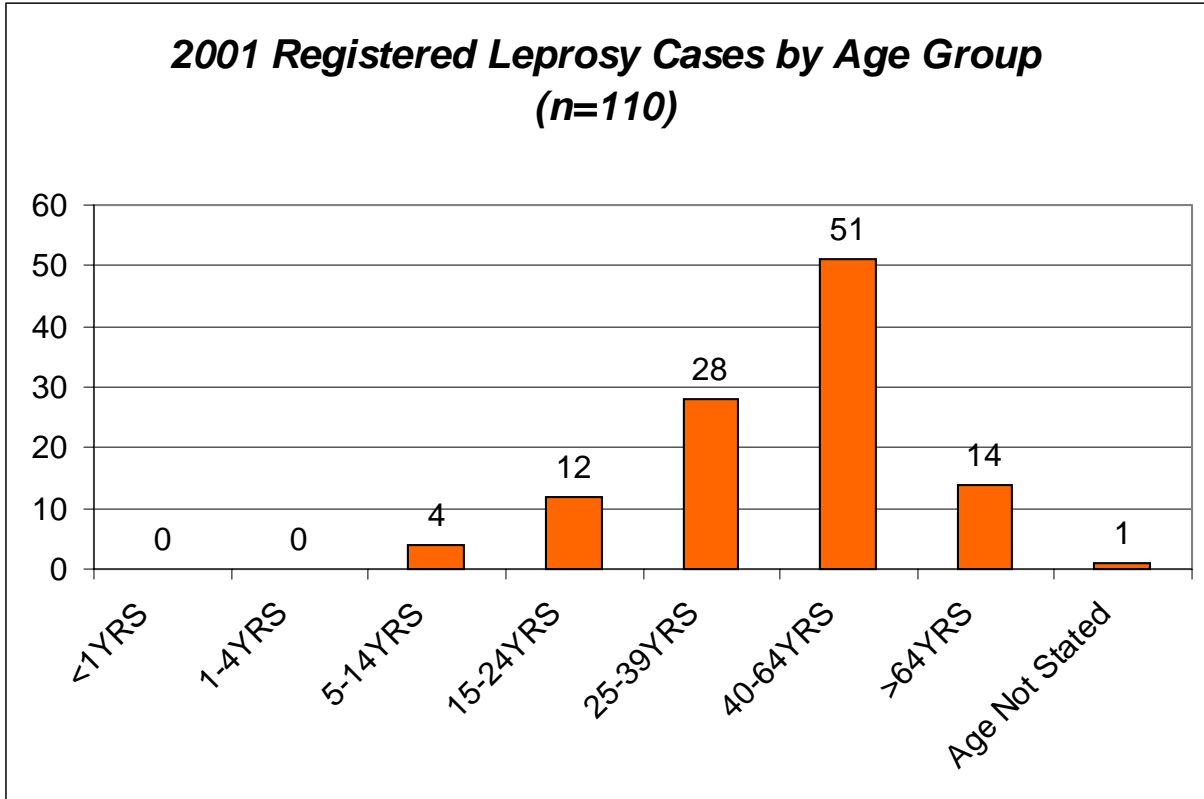


## Appendix 6

### ***2001 Registered Leprosy Patients by Gender (n=110)***

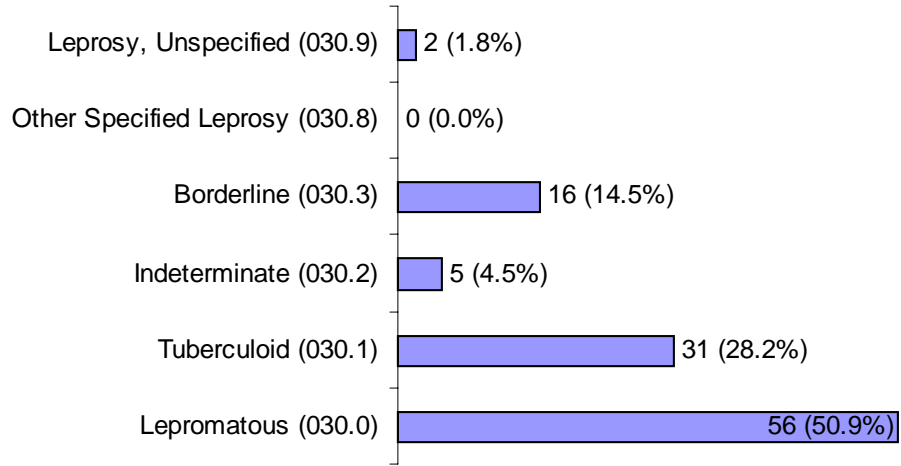


## Appendix 7



## Appendix 8

### **2001 Registered Leprosy Cases by ICD-9-CM Diagnosis Code (n=110)**



### **2001 Hansen's Disease Cases by Ridley-Jopling Classification**

INDETERMINATE	6
BORDERLINE TUBERCULOID	14
TUBERCULOID	18
BORDERLINE	5
BORDERLINE LEPROMATOUS	11
LEPROMATOUS	55
TOTAL	109

## Appendix 9

YEAR	CASES
1971	158
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

