Instructions for Completing the Hansen's Disease (Leprosy) Surveillance Form

The Hansen's Disease or Leprosy Surveillance Form *(LSF)* is the document used to report leprosy cases to the U.S. National Hansen's Disease Registry. These data are used for epidemiological, clinical, and basic research studies throughout the National Hansen's Disease Program *(NHDP)*, and are the official source for information on leprosy cases in the U.S.

The information requested on the LSF is used by many clinicians and researchers, and collection of all information is highly desirable. However, the fields that are **boldfaced** on the form and in the instructions below are considered to be the minimal information needed to register a patient. Failure to provide this information will result in the form being returned which creates additional work and may cause delays in obtaining program services for the patient.

- 1. **Reporting State:** Use the abbreviation of the state from which the report is being sent. This is usually the state of the clinician's office and not necessarily the patient's resident state.
- 2. Date of Report: This is date of the initial LSF completion. If patient was previously reported and has relapsed, write the word "RELAPSE" next to the date.
- 3. Social Security Number: self-explanatory.
- 4. Patient Name: Self-explanatory.
- 5. Present Address: Please include the county and zip code which are used to geographically cluster patients.
- 6. Place of Birth: Include state and county, if born in the U.S., or the country, if foreign born.
- 7. Date of Birth/Sex: Self-explanatory.
- 8. **Race/Ethnicity:** This information should be voluntarily provided by the patient. If the patient refuses or indicates a race/ethnicity category not listed, check the "Not Specified" box.
- 9. Date Entered the U.S.: For patients who have immigrated to the U.S., provide the month and year of entry.
- 10. Date of Onset of Symptoms: This information is usually the patient's recollection of when classic leprosy symptoms (rash, nodule formation, paresthesia, decreased peripheral sensation, etc.) were first noticed.
- 11. Date Leprosy First Diagnosed: Provide the month and year a diagnosis was made. This usually coincides with a biopsy date if one was performed.
- 12. Initial Diagnosis: Was the patient diagnosed in the U.S. or outside the U.S.
- 13. **Type of Leprosy:** Classify the diagnosis based on one of the ICD-9-CM diagnosis codes. (NHDP Clinic physicians: Please circle specific classification, if possible)

030.0 Lepromatous Leprosy (macular, diffuse, infiltrated, nodular, neuritic – includes Ridley-Jopling [RJ], Lepromatous [LL] and Borderline lepromatous [BL]): A form marked by erythematous macules, generalized papular and nodular lesions, and variously by upper respiratory infiltration, nodules on conjunctiva or sclera, and motor loss.

030.1 Tuberculoid Leprosy (macular, maculoanesthetic, major, minor, neuritic – includes RJTuberculoid [TT] and Borderline tuberculoid [BT]): A form marked by usually one lesion with well-defined margins with scaly surface and local tender cutaneous or peripheral nerves.

030.2 Indeterminate *(uncharacteristic, macular, neuritic)*: A form marked by one or more macular lesions, which may have slight erythema.

030.3 Borderline (*dimorphous, infiltrated, neuritic – includes RJ Borderline [BB] or true mid disease only):* A form marked by early nerve involvement and lesions of varying stages.

030.8 Other Specified Leprosy: Use this code when the diagnosis is specified as a "leprosy" but is not listed above (030.0-030.3).

030.9 Leprosy, Inactive: Use this code when the diagnosis is identified as a "leprosy" but inactive.

- 14. Diagnosis of Disease: Enter INITIAL biopsy and skin smear dates and results.
- 15. **Residence** (*Pre-diagnosis*): List all cities, counties, and states in the U.S. and all foreign countries a patient resided in BEFORE leprosy was diagnosed. This information is used to map all places where U.S. leprosy cases have resided.
- 16. Disability: Indicate any sensory abnormalities or deformities of the hands and feet or lagophthalmos of the eyes.
- 17. Current Household Contacts: Self-explanatory.
- 18. Current Treatment for Leprosy: Date treatment started and indicate all drugs used for initial treatment.
- 19. Name and Address of Physician or Investigator: Self-explanatory.

HANSEN'S DISEASE (LEPROSY) SURVEILLANCE FORM NATIONAL HANSEN'S DISEASE PROGRAMS

1770 PHYSICIANS PARK DRIVE

BATON ROUGE, LA 70816

1-800-642-2477

1 Reporting State		2 Date of Report Mo. Day Yr.				3 Social Security Number (optional)				
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4 Patient Name:	lame: (Last) (First)			(Middle)						
5 Present Address: Street				City						
County				State Zip						
6 Place of Birth:				7 Date of Birth: Sex:						
State County										
Country	White, Not Hispanic	White Liener	 	American l	ndian Alas		Indian Mid			
	White, Hispanic American I Black, Hispanic Asian, Pac					Not Specific	dle Easterner ed			
9 Date Entered U.S.:	Black, Not Hispanic	. · ·		Leprosy Fir		L	tial Diagnosis i			
Mo. Yr.	Mo. Yr.			Mo.	Yr.		_U.S.	Outside U.S.		
Tu	ed in U.S	BT) 🗌 Bo	orderline aces in th		BB) nd all forei			(030.9)		
BI: Positive Net 16 Disability: Hands Yes / No Sensory Loss Deformity	Eeet Eve Yes / No		+							
17 Current Household Co 1 2 3 4	ontacts: Name/Relatior					ate Treatment Dapsone Rifampin Clofazimine	Mo			

Investigator: