

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: Optional; 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 city, 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. **How many doctors have you seen for this problem?** This will be based primarily on the patient's recollection. Include the physician reporting the case.
13. **Initial Diagnosis:** Was the patient diagnosed in the U.S. or outside the U.S.
14. **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 RJ Tuberculoid [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 "leprosy" but is not listed above (*030.0-030.3*), including 'pure neural' disease.
 - 030.9 Leprosy, Inactive:** Use this code when the diagnosis is identified as "leprosy" but inactive.
15. **Diagnosis of Disease:** Reaction=Y if steroids required. Enter INITIAL biopsy and skin smear dates and results.
16. **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.
17. **Disability: Eye, Hand & Foot.** For each eye, hand and foot check Yes or No. [Normal always = No]
 - Loss of any sensation** in hands or feet; for Eyes, is blinking abnormal (very infrequent?). Normal = No
 - Visible deformity** (muscle wasting, clawing of fingers or toes, ulcers or other abnormality of the hands or feet). For Eyes, lagophthalmos or reduced vision (e.g. cataract). Normal = No
18. **Current Household Contacts:** Self-explanatory.
19. **Current Treatment for Leprosy:** Date that treatment started and indicate all drugs used for initial treatment.

HANSEN'S DISEASE (LEPROSY) SURVEILLANCE FORM
NATIONAL HANSEN'S DISEASE PROGRAMS
1770 PHYSICIANS PARK DRIVE
BATON ROUGE, LA 70816
1-800-642-2477

FOR NHDP USE ONLY

1 Reporting State: <div style="text-align: center;"> <input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/> </div>	2 Date of Report: <div style="display: flex; justify-content: space-around; font-size: small;"> Mo. Day Yr. </div> <div style="text-align: center;"> <input style="width: 20px; height: 20px;" type="text"/> </div>	3 Social Security Number (optional): <div style="text-align: center;"> <input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/> - <input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/> - <input style="width: 20px; height: 20px;" type="text"/> </div>
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4 Patient Name: _____
(Last)
(First)
(Middle)

5 Present Address: Street _____ City _____
County _____ State _____ Zip _____

6 Place of Birth: State _____ City _____ Country _____	7 Date of Birth: Sex: <input type="checkbox"/> Male <input type="checkbox"/> Female <div style="display: flex; justify-content: space-around; font-size: small;"> Mo. Day Yr. </div> <div style="text-align: center;"> <input style="width: 20px; height: 20px;" type="text"/> </div>
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8 Race/Ethnicity: White, Not Hispanic White, Hispanic American Indian, Alaska Native Indian, Middle Easterner
 Black, Not Hispanic Black, Hispanic Asian Native Pacific Islander Not Specified

9 Date Entered U.S.: <div style="display: flex; justify-content: space-around; font-size: small;"> Mo. Yr. </div> <div style="text-align: center;"> <input style="width: 20px; height: 20px;" type="text"/> </div>	10 Date of Onset of Symptoms: <div style="display: flex; justify-content: space-around; font-size: small;"> Mo. Yr. </div> <div style="text-align: center;"> <input style="width: 20px; height: 20px;" type="text"/> </div>	11 Date Leprosy First Diagnosed: <div style="display: flex; justify-content: space-around; font-size: small;"> Mo. Yr. </div> <div style="text-align: center;"> <input style="width: 20px; height: 20px;" type="text"/> </div>	12 How many doctors have you seen for this problem? <input type="text"/>	13 Initial Diagnosis: <input type="checkbox"/> In U.S. <input type="checkbox"/> Outside U.S.
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14 Type of Leprosy: (ICD-9-CM Code) (NHDP Clinic physicians: Please circle specific classification, if possible)
 Lepromatous (030.0 - LL, BL) Indeterminate (030.2 - IN) Other Specified Leprosy (030.8)
 Tuberculoid (030.1 - TT, BT) Borderline (030.3 - BB) Leprosy, Unspecified (030.9)

15 Diagnosis of Disease:

Leprosy reaction at diagnosis? Yes No

Was biopsy performed in U.S.? Yes No

Date ____ / ____ / ____

Result _____

Skin Smear? Yes No ____ / ____ / ____
Date

BI: Positive ____ Negative ____

16 List all places in the U.S.A. and all foreign countries a PATIENT resided (Including Military Service) BEFORE leprosy was diagnosed:

TOWN	COUNTY	STATE	COUNTRY	INCLUSIVE DATES	
				From Mo./Yr.	To Mo./Yr.

17 Disability: Loss of Sensation? Visible deformity?	Hands				Feet				Blink abnormal? Lagophthalmos?	Eyes			
	Right		Left		Right		Left			Right		Left	
	Yes	No	Yes	No	Yes	No	Yes	No		Yes	No	Yes	No
	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>							

18 Current Household Contacts: Name/Relationship

1 _____

2 _____

3 _____

4 _____

19 Current Treatment for Leprosy: (check all that apply)

Date Treatment Started: ____ / ____
Mo.
Yr.

Dapsone Rifampin Clofazimine

Other (list) _____

20 Name and Address of Physician: _____

Investigator: _____