

12-ID-01

Committee: Infectious Disease

Title: Update to Public Health Reporting and National Notification for Hansen's disease

I. Statement of the Problem

For many years, CDC's Hansen's disease surveillance data have not closely matched that collected by the National Hansen's Disease Program (NHDP) because variables collected by each agency are not standardized. NHDP assists with clinical case management, diagnostics, and provides free treatment to patients; as a result, case reporting to NHDP from health care providers tends to be more complete.

A position statement formalizing the case definition and classification, and to maintain public health surveillance of Hansen's disease, was approved by CSTE in 2010. Since 2010, CDC and NHDP have collaboratively developed a case report form which will allow for case matching received at CDC and NHDP, along with a case notification mechanism which aims to improve CDC's surveillance data, as well as ensure case-patients receive care through NHDP. This proposed revision to the 2010 position statement will provide NHDP contact information for diagnosis and treatment, describe an improved case notification mechanism, and update the case definition.

II. Background and Justification¹

Hansen's disease, commonly known as leprosy, is a chronic bacterial disease of the skin and peripheral nerves caused by *Mycobacterium leprae*. Although the mode of transmission of Hansen's disease remains uncertain, most investigators think that *M. leprae* is usually spread from person to person in respiratory droplets based on the fact that close contacts appear to bear the greatest risk of infection. Transmission of Hansen's disease in the United States is rare with ~200 cases reported each year. Most U.S. cases occur in immigrants, typically from Asia, the Asian Pacific Islands and Latin America. However, approximately 25% of U.S. cases are found in non-immigrants living in southern Louisiana and the Gulf coast of Texas and may be linked to armadillo contact. Symptoms may be present for years prior to diagnosis, creating a potential opportunity for ongoing transmission and confounding epidemiological studies. This chronic infectious disease usually affects the skin and peripheral nerves but has a wide range of possible clinical manifestations.

Ongoing surveillance is needed to facilitate case detection and control efforts; and awareness needs to be raised among physicians that Hansen's disease exists in the U.S. Improved case notification to both CDC and NHDP will ensure case-patients receive treatment, with the aim to improve health outcomes and decrease permanent disability.

III. Statement of the desired action(s) to be taken

1. CSTE recommends that States and Territories conducting surveillance according to these methods encourage health care providers to report case information to both the local or state health department for surveillance and to consult with the NHDP to initiate free provision of HD medications and laboratory services.
2. CSTE recommends that States and Territories conducting surveillance according to these methods report case information to CDC.

¹Much of the material in the background is directly quoted from the CDC's Hansen's disease website. See the References for further information on this source.

3. CSTE recommends that CDC publish data on Hansen’s disease as appropriate in MMWR and other venues.
4. CSTE recommends that CDC revise the surveillance case definition for Hansen’s disease infection as described below in Sections VI and VII

IV. Goals of Surveillance

To provide information on the temporal, geographic, and demographic occurrence of Hansen’s disease to facilitate its prevention and control. Federal collaboration to ensure case-patients receive treatment.

V. Methods for Surveillance: Surveillance for Hansen’s disease should use the following recommended sources of data and the extent of coverage listed in Table V.

Table V. Recommended sources of data for case identification and extent of coverage for ascertaining cases of Hansen’s disease.

Source of data for case identification	Coverage	
	Population-wide	Sentinel sites
Clinician reporting	X	
Laboratory reporting	X	
Reporting by other entities (e.g., hospitals, veterinarians, pharmacies)	X	
Death certificates		
Hospital discharge or outpatient records	X	
Extracts from electronic medical records	X	
Telephone survey		
School-based survey		
Other _____		

VI. Criteria for case identification

Reporting refers to the process of healthcare providers or institutions (e.g., clinical laboratories, hospitals) submitting basic information to governmental public health agencies about cases of illness that meet certain reporting requirements or criteria. The purpose of this section is to provide those criteria that should be used to determine whether a specific illness should be reported

A. Narrative: A description of suggested criteria that may be for case ascertainment of a specific condition.

Report any illness to public health authorities that meet any of the following criteria:

1. All persons with laboratory results which demonstrate:
 - Acid-fast bacilli in the skin or dermal nerve from a full-thickness biopsy of a skin lesion using Fite stain, or
 - Noncaseating granulomas with peripheral nerve involvement, and
 - Mycobacterial growth on conventional media (if done) is absent.
2. Diagnosis of Hansen’s disease and an anti-leprosy drug regimen is initiated or indicated

Other recommended reporting procedures

- Healthcare providers should consult with the NHDP about all cases of Hansen’s disease as soon as possible, in order to initiate free provision of HD medications and other laboratory services, as

well as clinical consultations. Cases should be reported to the National Hansen's Disease Program's (NHDP) report form or by calling the NHDP (1-800-642-2477, www.hrsa.gov/hansens).

- All cases of Hansen's disease reported to NHDP should be reported to the local and/or state health department.
- All cases of Hansen's disease should also be reported to the local and/or state health department, according to jurisdictional procedures. Some health departments may choose to use the NHDP report form to facilitate the collection of uniform data.
- De-identified case report forms should be sent to CDC by the state health department or sent electronically to the Nationally Notifiable Disease Surveillance System.
- Reporting should be on-going and routine.
- Frequency of reporting should follow the state health department's routine schedule.

B. Table of criteria to determine whether a case should be reported to public health authorities

Table VI-B. Table of criteria to determine whether a case should be reported to public health authorities.

Criterion	Reporting	
<i>Clinical Presentation</i>		
Diagnosis of Hansen's disease		N
Placement on an anti-leprosy drug regimen, or anti-leprosy drug regimen is indicated		O
<i>Laboratory findings</i>		
Using Fite stain: Acid fast bacilli demonstrated in skin	S*	
Acid-fast bacilli in dermal nerve	S*	
Identification of noncaseating granulomas with peripheral nerve involvement	S*	
Mycobacterial growth on conventional media, if done	A	

Notes:

Meeting the criteria listed under any single column of this table is sufficient to identify a case for reporting.

S = This criterion alone is sufficient to report a case

N = This criterion in conjunction with all other "N" and any "O" criteria in the same column is required to report a case.

O = At least one of these "O" (Optional) criteria in each category (e.g., clinical evidence and laboratory evidence) in the same column—in conjunction with all "N" criteria in the same column—is required to report a case.

A = This criterion must be absent (i.e., NOT present) for the case to meet the reporting criteria.

* A requisition or order for any of the "S" laboratory tests is sufficient to meet the reporting criteria.

C. Disease-specific data elements

Disease-specific data elements to be included in the initial report are listed below.

Epidemiological Risk Factors

Country of birth

Date first entered U.S.

Initial diagnosis in [U.S. or outside U.S.]

Type of leprosy

Biopsy/Skin smear results

Bacilli present

Disability scores

Places in U.S. and foreign countries where patient resided for >3 months
 Contact with a confirmed case of Hansen’s disease
 Armadillo contact

VII. Case Definition for Case Classification

A. Narrative: Description of criteria to determine how a case should be classified.

Clinical criteria

A chronic bacterial disease characterized by the involvement primarily of skin as well as peripheral nerves and the mucosa of the upper airway. Clinical forms of Hansen's disease represent a spectrum reflecting the cellular immune response to *Mycobacterium leprae*. The following characteristics are typical of the major forms of the disease, *though these classifications are assigned after a case has been laboratory confirmed.*

- *Tuberculoid*: one or a few well-demarcated, hypopigmented, and hypoesthetic or anesthetic skin lesions, frequently with active, spreading edges and a clearing center; peripheral nerve swelling or thickening also may occur
- *Lepromatous*: a number of erythematous papules and nodules or an infiltration of the face, hands, and feet with lesions in a bilateral and symmetrical distribution that progress to thickening of the skin, possibly with reduced sensation.
- *Borderline (dimorphous)*: skin lesions characteristic of both the tuberculoid and lepromatous forms
- *Indeterminate*: early lesions, usually hypopigmented macules, without developed tuberculoid or lepromatous features but with definite identification of acid-fast bacilli in Fite stained sections

Laboratory criteria for diagnosis

Confirmatory:

- Demonstration of acid fast bacilli in skin or dermal nerve from a biopsy of a skin lesion using Fite stain, without growth of mycobacteria on conventional media (if done).
- OR
- Identification of noncaseating granulomas with peripheral nerve involvement, without growth of mycobacteria on conventional media (if done).

Case classification

Confirmed:

A clinically compatible illness with confirmatory laboratory results.

B. Classification Tables

Table VII-B.Criteria for defining a case of Hansen’s disease.

Criterion	Case Definition
	Confirmed
<i>Clinical Presentation</i>	
Skin lesions that are well-demarcated, hypopigmented, and hypoesthetic or anesthetic—one or a few	○
Skin lesions with active, spreading edges and a clearing center	○
Erythematous nodules	○
Erythematous papules	○

Skin lesions which infiltrate the face, hands, and feet in a bilateral and symmetrical distribution with or without reduced sensation	O
Thickening of the skin	O
Peripheral nerve swelling	O
Peripheral nerve thickening	O
Hypopigmented macules, without developed tuberculoid or lepromatous features	O
Laboratory findings	
Using Fite stain: Acid-fast bacilli in dermal nerve	S
Using Fite stain: Acid fast bacilli demonstrated in skin	S
Mycobacterial growth on conventional media, if done	A
Identification of noncaseating granulomas with peripheral nerve involvement	S

Notes:

Meeting the criteria listed under any single column of this table is sufficient to identify a case for reporting.

S = This criterion alone is sufficient to report a case

N = This criterion in conjunction with all other “N” and any “O” criteria in the same column is required to report a case.

O = At least one of these “O” (Optional) criteria in each category (e.g., clinical evidence and laboratory evidence) in the same column—in conjunction with all “N” criteria in the same column—is required to report a case.

A = This criterion (if done) must be absent (i.e., NOT present) for the case to meet the reporting criteria.

* A requisition or order for any of the “S” laboratory tests is sufficient to meet the reporting criteria.

VIII. Period of Surveillance

Surveillance should be on-going.

IX. Data sharing/release and print criteria

- Communication with NHDP and notification to CDC of cases of confirmed Hansen’s disease is recommended.
- Electronic reports of Hansen’s disease cases in NNDSS are summarized weekly in the MMWR Tables.
- Annual case data on Hansen’s disease is also summarized in the annual Summary of Notifiable Diseases.
- State-specific compiled data will continue to be published in the weekly reports and annual MMWR Surveillance Summaries.
- The frequency of release of additional publications of these data will be dependent on the current epidemiologic situation in the country. These publications might include annual epidemiologic summaries in the MMWR or manuscripts in peer-reviewed journals.
- Aggregate case data will be shared with WHO as requested.

X. References

Council of State and Territorial Epidemiologists (CSTE).Public Health Reporting and National Notification for Hansen’s Disease. CSTE position statement 10-ID-12. June 2010. Available from:
<http://www.cste.org/ps2010/10-ID-12.pdf>.

Centers for Disease Control and Prevention (CDC).Case definitions for infectious conditions under public health surveillance.MMWR 1997; 46 (No. RR-10):1–57. Available from:
<http://www.cdc.gov/mmwr/preview/mmwrhtml/00047449.htm>.



Centers for Disease Control and Prevention (CDC). National notifiable diseases surveillance system: case definitions. Atlanta: CDC. Available from: <http://www.cdc.gov/ncphi/diss/nndss/casedef/index.htm>
Last updated: 20010 Jan 12. Accessed: 29 March 2010.

Council of State and Territorial Epidemiologists (CSTE).CSTE official list of nationally notifiable conditions.CSTE position statement 07-EC-02. Atlanta: CSTE; June 2007. Available from:
<http://www.cste.org>.

Council of State and Territorial Epidemiologists (CSTE).Criteria for inclusion of conditions on CSTE nationally notifiable condition list and for categorization as immediately or routinely notifiable.CSTE position statement 08-EC-02. Atlanta: CSTE; June 2008. Available from: <http://www.cste.org>.

Council of State and Territorial Epidemiologists (CSTE).Revised Case Definitions for Public Health Surveillance: Infectious Disease. 1996-18. Atlanta: CSTE; June 1996. Available from:
<http://www.cste.org>.

Council of State and Territorial Epidemiologists (CSTE).Data Release Guidelines of the Council of State & Territorial Epidemiologists for the National Public Health System.Atlanta: CSTE; June 1996.

Council of State and Territorial Epidemiologists, Centers for Disease Control and Prevention. CDC-CSTE Intergovernmental Data Release Guidelines Working Group (DRGWG) Report: CDC-ATSDR Data Release Guidelines and Procedures for Re-release of State-Provided Data. Atlanta: CSTE; 2005. Available from: <http://www.cste.org/pdffiles/2005/drgwgreport.pdf> or <http://www.cdc.gov/od/foia/policies/drgwg.pdf>.

Heymann DL, editor. Control of communicable diseases manual.18th edition. Washington: American Public Health Association; 2004.

Scollard, D.M., Adams, L.B., Gillis, T.P., Krahenbuhl, J.L., Truman, R.T., and Williams, D.L. The Continuing Challenges of Leprosy. *Clinical Microbiology Reviews*, 19: 338-381, 2006.
Jacobson, R. and J.L. Krahenbuhl.Overview of Leprosy.UpToDate CD-ROM, 16.0; 2009

XI. Coordination

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