

A MANUAL FOR THE CARE OF

HANSEN'S DISEASE

IN THE UNITED STATES

Adopted by the Texas Department of State Health Services
Hansen's Disease Program, September 1, 2013

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NATIONAL HANSEN'S DISEASE PROGRAM

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INTRODUCTION

MISSION

The National Hansen's Disease Program (NHDP) is an activity in the Department of Health and Human Services (DHHS), Health Resources and Services Administration (HRSA), and the Healthcare Systems Bureau. It is authorized by Public Law 99-117, Section 2. (a), Section 320 and is guided by DHHS regulations. The NHDP is charged with the responsibility of providing Hansen's disease (HD) treatment for individuals with this disease through the NHDP, in Baton Rouge, Louisiana, and through its Ambulatory Care Program.

ELIGIBILITY

Any individual living in the United States and Puerto Rico may receive outpatient medical care for the diagnosis and treatment of HD and its complications. Contacts of these patients are also eligible for services as described by NHDP policy (see "Contact Surveillance" in this Manual)

OBJECTIVE

The goal of the National Hansen's Disease Program is to prevent deformity and disability from HD through early diagnosis and treatment. The purpose of this Manual is to serve as a resource for the diagnosis, care, and treatment of HD in the United States (U.S.).

BACKGROUND

The NHDP in the United States has a 100-year history of caring for people diagnosed with this disease. It began in 1896 in Carville, Louisiana, with the Daughters of Charity of St. Vincent de Paul who provided basic services to a small group of patients from New Orleans. In 1921 it became the federally-funded Gillis W. Long Hansen's Disease Center and the only inpatient facility for HD in the country.

In the early 40's, the use of sulfone therapy by Dr. Guy Faget at the Center resulted in the development of dapsone as a bactericidal agent against Mycobacterium leprae, the organism that causes the disease. This led to the greatest change in patient care, for patients could now be discharged from "Carville" and new patients could be treated on an outpatient basis.

The year 1960 Dr. Paul Brand, FRCS, FACS, an orthopedic surgeon, initiated rehabilitative procedures at Carville which effectively decreased the frequency of amputation of the lower extremities. These procedures have been incorporated into what is now LEAP, or Lower Extremity Amputation Prevention, the core of the Foot Seminars at the NHDP.

In 1981, the Federal Government initiated the Ambulatory Care Program (ACP), which provides HD medical care through Outpatient Clinics in the U.S. and Puerto Rico. Services provided by these Clinics include diagnosis and treatment of HD and related conditions, laboratory monitoring, consultant services, and patient and community education.

In January, 2000, the NHDP relocated its services at Carville to Ochsner Medical Center campus in Baton Rouge, LA, and now functions as the primary Outpatient Referral Center for the diagnosis and treatment of HD.

EPIDEMIOLOGY

The NHDP has responsibility for the National Hansen's Disease Registry, which is maintained through the submission of HD Surveillance Forms by private providers, and from the Outpatient HD clinics. California, Florida, Hawaii, Louisiana, Massachusetts, New York, and Texas collectively accounted for the largest number of the total reported cases. Although the number of cases reported annually is affected considerably by immigration patterns, the average number of annual cases reported over the past decade is 130.5.

Hansen's disease occurs in all age groups with a U.S. median age at diagnosis of 35.0 years. The disease exhibits a gender bias with twice as many male cases as female. A race/ethnicity breakdown shows that three fourths of the reported cases are represented by the Asian/Pacific Islander and White Hispanic groups, but fully 50% of the endemic cases are classified as White, Not Hispanic. (See "Data & Statistics" at www.hrsa.gov/hansensdisease 3 for more information)

BACTERIOLOGY

HD is caused by Mycobacterium leprae, a slow-growing, acid-fast bacillus. The incubation period for HD may be two-five years, although it can be as long as 15-20 years or more. The disease is probably spread through airborne droplets from the nasal mucosa and upper airways of a person with untreated disease, or through prolonged skin contact with this person. Armadillos may also carry the disease. The communicability of HD is very low, however, and about 95% of the world's population has a natural immunity to this bacillus. A person with HD becomes non-communicable within one week of starting treatment.

MANAGEMENT OF HANSEN'S DISEASE

CLINICAL ASPECTS OF HANSEN'S DISEASE

HD affects the skin, peripheral nerves, eyes, and mucous membranes of the upper respiratory tract, especially the nose. Nerve damage caused by the bacillus may result in anesthesia and deformities of the hands and feet and lagophthalmos of the eyes. In lepromatous HD there may be iritis, direct invasion of the anterior part of the eye by the bacilli, and in males, it may cause testicular atrophy and gynecomastia. A complete physical assessment of the patient is necessary.

In most people, resistance develops to infection with *M. leprae*. The body's defenses kill the invading bacteria, or contain the infection so disease does not develop. In persons with limited or no resistance to the disease, the bacteria grow slowly, eventually leading to the appearance of symptoms. Presence of the bacteria will be demonstrated with skin smears or biopsy.

Hypo- or hyper-pigmented, flat or raised lesions appear, which are insensitive to light touch. These are most commonly found on the buttocks, thighs, trunk, and lateral aspect of the upper and lower extremities. There may be anhidrosis, loss of hair on the skin, and changes in skin texture. The earlobes may be swollen and pendulous.

Patients may experience inflammation of the eyes, excessive or decreased tearing, loss of corneal sensation and lateral eyebrows, and incomplete closure of the eyelids.

Muscle strength of the hands and feet may be affected. There may be dryness, decreased sensation, muscle atrophy, deformity such as clawing of fingers or toes, wounds, and ulcers. Male patients may have painful, swollen testicles or gynecomastia.

Peripheral nerves may be enlarged or tender. The ulnar, median, radial cutaneous, posterior tibial, peroneal, and greater auricular are most commonly affected. Some patients complain of pain in the extremities, and a burning sensation in the soles of the feet. Abnormal nerves will feel sclerosed.

Effects of Hansen's Disease on Peripheral Nerves

Disability and deformity in HD are primarily due to nerve damage. The damage is caused by bacilli in the perineurium, the influx of inflammatory cells, the sheer bulk of bacillary material in both Schwann cells and invading macrophages, and by fibrosis occurring in the inflamed nerve. In addition to sensory loss or muscle paralysis, other effects of this denervation are anhidrosis and decreased oil production in the skin. This causes the skin to become dry and inelastic, leading to difficulties in healing when trauma occurs. The functionally important nerves most commonly damaged are the facial, ulnar, median, radial, peroneal, and posterior tibial.

Most of the disability and deformity in HD is secondary due to repetitive trauma and infection of insensitive areas. These secondary effects of nerve damage are preventable. Persons with normal sensation rely on the sense of pain to warn them of possible trauma and are able to prevent serious injury. Those who have lost sensation have to learn other methods to protect insensitive areas from injury. The specific psychological effects associated with a significant loss of sensation also need to be considered.

The Peripheral Nerves

- The Facial Nerve - The orbicularis muscle, innervated by the facial nerve, is sometimes affected in persons with HD. Damage to this nerve results in lagophthalmos, exposing the cornea to possible damage, especially during sleep. Loss of corneal sensation will compound the problem because the blink reflex may be compromised.

- Ulnar, Median, and Radial Nerves - Most commonly, the ulnar nerve is involved at the elbow and the wrist, and the median nerve is damaged just proximal to the wrist and in the carpal tunnel. Early signs are dryness of the hands, callus formation, and signs of trauma due to insensitivity, such as burns. The result of severe nerve damage will be atrophy of the intrinsic muscles of the hand, including the hypothenar and thenar areas. There may be clawing of the digits and weakness of pinch (ulnar) loss of opposition of the thumb (median), and wrist drop (radial).
- Peroneal and Posterior Tibial Nerve - Damage to the peroneal nerve causes anesthesia in the lateral aspect of the lower extremities and dorsum of the feet. The motor deficit is in the peroneal muscles and dorsiflexors of the foot; the earliest sign is difficulty in dorsiflexion or eversion of the foot against pressure. The result of a full motor deficit in this area is foot drop. Damage to the posterior tibial nerve will result in anesthesia of the plantar surface of the foot, and claw toes. Observe for a high-stepping, inverted gait, callus formation on the toes and plantar surface, and erythematous or warm pressure areas on the foot.
- Sensory Testing of Hands and Feet - Sensory testing of hands and feet with nylon filament should be done at the time of diagnosis and periodically during treatment to detect evidence of nerve damage at the earliest possible stages. This is an important part of disability prevention. Early detection of problems makes it possible to take steps which can prevent further nerve damage.

Surgery

Most patients with HD do not require any surgery but there are occasional situations in which the following surgical procedures may assist in therapy or rehabilitation:

- Incision and Drainage
- Tendon transfer procedure
- Surgical release of nerves
- Procedures for stabilization of Charcot foot.

Silent Neuritis

There are some patients who have no signs of reaction or nerve pain, but continue to have progressive sensory or motor loss in hands or feet. Such patients need to be assessed to determine that they are receiving appropriate chemotherapy since noncompliance with drug intake could contribute to this problem. However, there are still some patients who are taking their medications regularly and still have deteriorating nerve function. The cause of this deterioration is not known, but some of these patients will have improvement if they receive steroid treatment. If the loss of function has been 3 months or less, they should be given a course of steroids in the dose range for reactions. If the loss has been present for longer than 3 months the chance of recovery is diminished. Therefore, it is important to monitor all patients under treatment for any changes in nerve function and treat accordingly.

HD and Pregnancy

A female with HD who is pregnant is rare in the U.S., but a few cases occur each year. The majority of these pregnancies are uneventful as far as HD is concerned, but there are a number of potential problems and risks that should be considered when advising female HD patients of childbearing age, and when managing patients who are already pregnant and have HD.

All female patients of childbearing age should be advised to avoid pregnancy during early stages of the disease, at least until MDT has been completed and preferably until the disease is completely inactive. The postponement of pregnancy is especially important for patients who have evidence of reaction or neuritis since these problems will be exacerbated during pregnancy and the postpartum period. There may also be a very small risk of transmission of the disease from mother to infant in those cases where the pregnancy occurs before treatment or early in the course of treatment.

There are alterations in the immune response during all pregnancies, causing a depression of the cell-mediated immune system. This immune suppression during pregnancy and its recovery in the postpartum period appears to play a role in the clinical manifestations of HD in women. It is common for the first symptoms of HD in young women to occur during pregnancy or the postpartum period. An increased risk of relapse during pregnancy has also been reported.

ENL is more common during pregnancy when the CMI is depressed, while reversal reaction is more common during the postpartum period when the CMI is recovering.

The risk of reactions or neuritis during pregnancy will vary considerably with the type of disease and the amount of treatment a patient has received prior to the pregnancy. If a reaction occurs during a pregnancy, it should be managed as in non-pregnant patients with the use of prednisone sufficient to control the reaction and prevent nerve damage. Thalidomide cannot be used.

For patients who are or become pregnant during the early stages of the disease, chemotherapy should generally continue during pregnancy with some modification of the regimens in some cases. We avoid the use of rifampin during pregnancy if possible. Dapsone can be continued throughout the pregnancy.

Patients who have had HD sometime in the past, who have been adequately treated, and whose disease is now completely inactive, can be expected to have essentially normal pregnancies. There is no risk of the mother transmitting the disease to infants in such cases.

HD and Children

HD in children is uncommon in the U.S., but does occur and is usually indeterminate or tuberculoid type disease. It is usually a benign disease with very few deformities reported. Management of the disease is generally the same as for adults except for the adjustment of drug dosages to be determined by the physician. Transmission of HD to children should not occur after the adult patient starts on treatment that includes rifampin. Preventive treatment is not generally recommended for child contacts. The presence of new cases in children usually indicates that HD is still being transmitted in the general population.

Testicular HD

Direct invasion of the testicles probably occurs in most cases of Borderline and Lepromatous disease, although testicular dysfunction is most common in Lepromatous disease. The testicles are a cool part of the body and are preferentially affected. If HD is not treated early, there is progressive destruction of testicular tissue and eventually testicular atrophy with sterility and a decrease in testosterone production.

Gynecomastia usually develops relatively late and is an indication of advanced disease. Acute orchitis may develop during ENL and may be an indication for prednisone therapy. Testicular atrophy is usually permanent. After testicular function is destroyed, the only treatment is testosterone replacement. This does not restore fertility but is helpful in restoring sexual potency. Injectables are the preferred route for replacement therapy. Oral androgens are not recommended for long-term therapy because of potential liver toxicity.

DIAGNOSTIC CRITERIA

In the U.S., HD is diagnosed through biopsy of a skin lesion associated with loss of sensation.

SCHEDULE OF SERVICES

I. New Patient

- A. Patient Interview
- B. HD Monitors
- C. Medical Assessment
- D. Biopsy
- E. Skin Smears (optional)
- F. Baseline laboratory studies
- G. Hand and Foot Screens
- H. HD Surveillance Form
- I. HD Patient Education

II. Follow-Up Visit

- A. Patient Interview
- B. HD Monitors
- C. Medical Assessment
- D. Laboratory monitoring (See Lab Monitoring below for schedule)
- E. Annual biopsy is recommended
- F. Skin Smears annually (optional)
- G. Hand and Foot Screens (See Frequency of Performance in Appendix)
- H. Patient Education every clinic visit

PATIENT ASSESSMENT

I. Patient Interview

A. Family History of HD

B. Presenting Symptoms

1. No pain reported with injuries such as cuts or burns
2. Recurrent nosebleeds
3. Chronic nasal congestion
4. Burning sensation on soles of feet or hands
5. Painful / tender peripheral nerves

C. Psychological considerations

1. Stigma/myths
2. Living with the diagnosis-family, friends, boss, colleagues
3. Common concerns-cause, treatment, contagiousness, sexual relations, deformities

II. Physical Assessment

A. Skin-It is important to perform a complete examination of the skin in good light. Hypo-pigmented or hyper-pigmented flat or raised lesions may be found on the face, trunk, extremities, buttocks, or thighs. Absence of sweating, hair loss, or changes in texture of the skin may also be present. Ask male patients about pain or swelling of the testicles and examine for erythematous nodules.

B. Eyes-Examine the eyes for inflammation, incomplete closure of the eyelids, and pupil size. In patients with borderline lepromatous disease, an ophthalmological exam should be done to rule out eye involvement.

C. Nerves-A peripheral nerve assessment should be done to determine if nerves are enlarged or tender (See Appendix). The ulnar, median, radial cutaneous, posterior tibial, and peroneal nerves are commonly affected. In patients with anesthesia of the hands or feet, ulcerations, muscle atrophy, or deformity may be present. A common complaint is pain in the extremities and a burning sensation in the soles of the feet.

D. Hands and Feet-Hands and feet should be examined for dryness, diminished sensation, muscle weakness or muscle atrophy, wounds, and ulcers.

E. HD Monitors-The purpose of this exam is to perform a visual inspection and assessment of motor function of the eyes, hands, and feet of a patient with HD. It is an excellent venue for teaching patients about the prevention of complications. (See Appendix for procedure)

LABORATORY MONITORING

I. Recommended Laboratory Tests and Frequency

	Initial visit	2nd visit (1-2 months)	3 m	6 m	12 m	18 m	24 m
CBC + platelets	X	X	X	X	X	X	X
AST	X		X	X	X	X	X
ALT	X		X	X	X	X	X
CRP	X	X	X	X	X	X	X
BUN	X						
Creatinine	X						
Bilirubin	X						
G6PD	X						
Hepatitis B*							
Hepatitis C*							

*Screen for these or other co-morbidities if patient requires prednisone for reaction

II. Other tests

- A. UA should be done annually with these studies for all patients.
- B. PCR Assay (Polymerase Chain Reaction)
In a non-endemic population, the sensitivity and specificity of PCR assay recommend its use primarily to identify *M.leprae* when acid-fast organisms are discernible but atypical clinical or histopathologic features are obscuring the diagnosis. The Assay is not highly informative when acid-fast bacilli are not detectable by light microscopy. (Am J Clin Pathol 1998; 109:642-646) To further determine whether this Assay would be clinically appropriate, contact Dr. David Scollard, Chief, Clinical Branch NHDP, at 225-756-3713.

TREATMENT OF HD IN THE U.S.

I. Clinical Spectrum of HD

The clinical features of HD cover a wide range, from a single hypo-pigmented skin macule to generalized disease. Wide differences are seen in the pathological features, immunological status, treatment required, and types of complications that develop. For treatment purposes, the NHDP uses the WHO two-group classification, into which the Ridley-Jopling five-group classification is incorporated.

- A. Indeterminate (I) HD is the earliest stage of disease, and consists of one or two vague hypo-pigmented macules, slightly dry in texture, with anhidrosis, and generally, no *M.leprae* in the lesion. Over half of these cases resolve without treatment, others progress eventually into one of the other forms of HD.

- B. Tuberculoid (TT) is limited disease with few, well-defined hypo-pigmented skin lesions which have marked sensory loss. Loss of hair in the lesion is common and there is often central healing. Without treatment, lesions may enlarge slowly, or self-heal. M.leprae are few or hard to find, but peripheral nerve involvement is common, leading to severe disabilities if nerve damage occurs.
- C. Borderline (BT, BB, BL) disease has features of both the tuberculoid and lepromatous types of HD. Skin lesions occur in small and large sizes and may be hypo- or hyper-pigmented. These lesions may or may not be anesthetic.
- D. Lepromatous (LL) type disease is characterized by lesions which are numerous, small, and symmetrically distributed. They may be hypo- or hyper-pigmented. The skin, nerves, bones, eyes, and nasal area are most often affected; however, all organs may become involved. There may be elongated ear lobes with partial or complete loss of the eyebrows, and anhidrosis of some parts of the body.

II. Treatment

Treatment of HD involves more than simply prescribing medication. Good health education at the time of diagnosis and during the course of treatment will make it more likely that the patient will have a better outcome. Thus, an important part of the management of HD is providing accurate information to patients and families regarding the expected course and prognosis of the disease.

A. Recommended Treatment Regimens

Following are the general NHDP recommendations for the treatment of persons with HD in the U.S. NHDP recommendations are for daily rifampin, and for longer duration of treatment than the WHO recommendations. Treatment that is more intensive and of longer duration is medically preferable.

Treatment guidelines for immunologically competent individuals, (e.g. those without immunodeficiency, immunosuppression, prolonged corticosteroid use, etc.) are as follows:

Adults		
Tuberculoid (TT & BT) (WHO classification Paucibacillary, "PB")		
Agent	Dose	Duration
Dapsone	100 mg daily	12 months, and <u>then therapy discontinued</u>
Rifampicin	600 mg daily	

Adults		
Lepromatous (LL, BL, BB) (WHO classification Multibacillary, "MB")		
Agent	Dose	Duration ^a
Dapsone	100 mg daily	24 months, and <u>then therapy discontinued</u>
Rifampicin	600 mg daily	
Clofazimine ^b	50 mg daily	

For immunologically compromised patients, these protocols may be modified, and consultation with the NHDP is recommended.

- a. The recommended durations of treatment are sufficient, even though large numbers of dead bacilli may remain in the tissues for several years, before they are eliminated by physiological processes. There is no evidence that additional, prolonged treatment hastens the elimination of these dead organisms.
- b. Clofazimine, used for decades to treat HD around the world, is no longer available on the open market. Because it is no longer distributed commercially, the only way we can obtain the drug in the U.S. is to once again treat it as an investigational new drug (IND). The NHDP holds this IND for its use in treating HD in the U.S.

B. In order for physicians to obtain the drug for treating HD, they will have to be registered as an investigator under the NHDP IND. This will require submitting a signed FDA form 1572 and a curriculum vitae to the NHDP. A packet of information including the form 1572 as well as consent forms, etc., will be provided. An Institutional Review Board (IRB) of the Centers for Disease Control has agreed to act as the central IRB for the use of Clofazimine for Hansen's Disease, so that individual physicians do not need to arrange this themselves. For further information, or to request investigator status to use Clofazimine, please call the NHDP at 1-800-642-2477.

C. ALTERNATIVE ANTI-MICROBIAL AGENTS

1. Minocycline, 100 mg daily, can be used as a substitute for Dapsone in individuals who do not tolerate this drug. It can also be used instead of Clofazimine, although evidence of the efficacy of its anti-inflammatory activity against Type 2 reactions is not as substantial as the evidence for Clofazimine.
2. Clarithromycin, 500 mg daily is also effective against *M. leprae*, and can be used as a substitute for any of the other drugs in a multiple drug regimen.
3. Ofloxacin, 400 mg daily, may also be used in place of Clofazimine, for adults. This is not recommended for children.

D. In the United States, the occurrence of leprosy in children is rare. We strongly recommend contacting the NHDP for management of leprosy in children; the following are general guidelines.

Treatment for children		
Tuberculoid (TT & BT) (WHO Paucibacillary, "PB")		
Agent	Dose	Duration
Dapsone	1 mg/ Kg daily	12 months, and <u>then therapy discontinued</u>
Rifampicin	10-20 mg/ Kg daily (not > 600)	

Treatment for children		
Lepromatous (LL, BL, BB) (WHO Multibacillary, "MB")		
Agent	Dose	Duration
Dapsone	1 mg/ Kg daily	24 months, and <u>then therapy discontinued</u>
Rifampicin	10-20 mg/ Kg daily (not > 600)	
Clofazimine ^c	1.0 mg/Kg daily ^c	

- c. As there is no formulation less than 50 mg, and the capsule should never be cut open, alternate day dosing may be used at 2 mg/kg.

E. Common Side-effects of HD medications

1. Dapsone
 - a. Contraindications-prior allergy to dapsone, 6PD deficiency, breast-Feeding
 - b. Side effects-hemolysis
2. Rifampin
 - a. Contraindications-prior allergy to rifampin
 - b. Side effects-abnormal liver function, thrombocytopenia, drug interactions with oral contraceptives and anticoagulants, reddish discoloration of urine, stools, saliva, tears, and sweat

3. Clofazimine

- a. Contraindications-none indicated
- b. Side effects-discoloration of skin, diarrhea, abdominal pain, and less commonly, bowel obstruction

On November 1, 2004, Novartis Pharmaceuticals Corporation ceased distribution of lamprone (clofazimine) in the U.S. through its usual distribution channels. It is only available now through Investigational New Drug (IND) protocol. To receive clofazimine for treatment of HD, you must be enrolled as an investigator under the IND held by CDC. To enroll, contact Catherine Crnko at:

Catherine Crnko, Administrative Officer
National Hansen's Disease Programs
ccrnko@hrsa.gov
1770 Physician Park Drive
Baton Rouge, LA 70816
Phone: (225) 756-3709, Fax (225) 756-3819

****Clofazimine** has been safely used in children and pregnant women for years. For questions regarding this process, please call Barbara Stryjewska,MD, Principal Investigator/Sponsor, at 1-800-642-2477.

New Drugs

Several new drugs have been studied and undergone small clinical trials. Larger clinical trials are now in progress. The most promising of these are ofloxacin, minocycline, and clarithromycin. Although these drugs are already marketed and available for other uses, at present there is only limited information on the use of these drugs in the treatment of HD. Therefore, they are not recommended as routine or first line anti-leprosy drugs at present. The main indication for their use at present would be in patients with drug intolerance for the currently recommended drugs or cases of documented drug resistance. It is important to make the best use of the drugs that are available to avoid increasing the problem of drug resistance.

D. Follow-Up after Completion of Treatment

Clinical examinations should be done at the following intervals:

- 1. Paucibacillary (PB) - Annually for three years
- 2. Multibacillary (MB)
 - a. Every six months for two years
 - b. Annually for eight years
- 3. Skin biopsies are recommended annually

REACTIONS IN HD

Although *M. leprae* is almost non-toxic, some patients develop acute hypersensitivity “reactions” to the organism. These are known as “lepra reactions”. Reports of the frequency of reactions indicate that 25% to 50% of all HD patients will have a reaction sometime during the course of the disease. There are no predictors of which patients will develop reaction, other than patients with tuberculoid disease do not have reactive episodes. Reactions are also less frequent in patients taking clofazimine. There are two types of reaction, Reversal Reaction or Type I Reaction, and Erythema Nodosum Leprosum, or ENL, which is Type II Reaction. For guidance on management of reaction, call the NHDP at 1-800-642-2477.

I. Symptoms of Reaction

- A. Neuritis-Enlarged or tender peripheral nerves; changes in sensation or strength
- B. Muscle weakness
- C. Tender, painful, erythematous nodules which may ulcerate
- D. Development of new lesions
- E. Malaise
- F. Fever-low-grade to moderate
- G. Red, painful eyes
- H. Orchitis in patients with multibacillary disease
- I. Edema of hands and feet

II. Treatment of Reactions

Reactions are a major cause of nerve damage, so the focus of management should be on the prevention of nerve damage. Damage to the nerves is caused by the tissue response within the nerves to intraneural *M. leprae* and is similar to the process seen in the skin. In untreated HD without reaction, nerve damage is more insidious, while in reaction, nerves may be damaged more rapidly. Skin reactions and acute neuritis often occur together. Antibacterial treatment should be continued at full dosage.

Patients with mild reaction may be treated symptomatically. Those with moderate to severe reaction may require steroids, thalidomide, or clofazimine. Patients with severe reaction, especially those with evidence of nerve damage, require treatment with corticosteroids. Some patients may require high doses of corticosteroids to control reaction and prevent nerve damage. They should have a baseline Bone Density test prior to initiating extended therapy with high doses of corticosteroids.

A. Treatment with steroids

1. Contraindications

- a. Inadequately treated infection
- b. Situation where medically supervised stoppage of medication is not possible

- c. Prolonged usage without close medical supervision
- 2. Side effects
 - a. Weight gain or potassium loss
 - b. New infection or exposure to an infectious person
 - c. Poor response to some immunizations
 - d. Interaction with laboratory or medical procedures such as blood sugar and TB skin tests
 - e. Withdrawal effects

- B. Thalidomide is very effective in controlling ENL, and is the drug of first choice if not contraindicated. This drug is very teratogenic and causes severe birth defects if taken by women during pregnancy.

In the U.S., Thalidomide is available to the prescribing physician and the dispensing pharmacist by registering with Celgene's System for Thalidomide Education and Prescribing Safety (STEPS) program. Male patients taking this medication must use prophylactics during sexual intercourse. Pregnancy tests at regular intervals are required for female patients of childbearing age.

- 1. Contraindications
 - a. Pregnancy
 - b. No unauthorized person may take this medication
- 2. Side effects
 - a. Fetal developmental defects
 - b. Constipation
 - c. Drowsiness
 - d. Dizziness

- C. Clofazimine can be given in a dose of 300mg daily for four to six weeks, reduced to 200 mg daily for several months, and then reduced to 100mg daily. The addition of clofazimine at these doses will usually make it possible to reduce the dose of steroids required, but not eliminate them entirely. Clofazimine is not quick acting and it may take six weeks or more for the full effect on the reaction to be noted. Patients receiving larger doses of clofazimine will have more severe skin pigmentation and more frequent gastro-intestinal side effects.

When the patient has required no steroids for approximately three months, the dosage of clofazimine can be reduced to 50mg daily. If clofazimine is not required for antibacterial treatment, it can be discontinued when no steroids have been required for an additional three months.

For consultation on the treatment of reaction, call the NHDP at 1-800-642-2477.

REHABILITATION SERVICES

I. Hand and Foot Rehabilitation Services

An efficient and comprehensive rehabilitation program in the management of insensitve limbs shall incorporate physical therapy, occupational therapy, pedorthics, and patient education. Rehabilitation goals aimed at minimizing loss of function, ulceration, amputation, and ultimate disability, can be satisfactorily achieved utilizing the following interdisciplinary rehabilitation practices: hand and foot care, exercise, wound care, splinting, casting, recommending assistive devices, follow-up therapy for HD orthopedic procedures, and in collaboration with the medical staff, identifying candidates for reconstructive surgery.

Disability prevention is promoted by the visual inspection of the hands, and feet of the patient at each encounter. If the hand or foot requires further evaluation, a hand or foot screen and palpation of the nerves shall be done. (See appendix, HD Manual for procedures.)

For patients scheduled to receive care at the NHDP in Baton Rouge, the Ambulatory Care therapist coordinates care with the NHDP therapists. Preoperative casting, wound care and postoperative rehabilitation provided by the therapist in the Ambulatory Care setting decreases the length of stay required for care at the NHDP.

A. Occupational Therapy

1. **Hand Screens** – These are a means of assessing the HD patient's risk category for hand problems, and for developing a care plan for their prevention and treatment.
2. The sensory testing device used with the Hand Screen is a set of five (5) calibrated nylon filaments mounted on a small rod, which measure levels of cutaneous touch and pressure on a scale of 2.83 to 6.65. The normal threshold level is 2.83.

B. Physical Therapy

1. **Foot Screens** – The Foot Screen has been proven to accurately identify patients who are at risk of developing deformities as a result of insensitivity, and also provides a baseline for determining the extent of foot disabilities.
2. The sensory testing device used with the Foot Screen is a nylon filament mounted on a holder designed to deliver a 10 gram force when properly applied. Our research has shown that a patient can feel the 10 gram filament in the selected sites will not develop ulcers.

(3) Frequency of Performance:

1. Hand and foot screens shall be done for new patients at the time of diagnosis, and on a quarterly basis as patients are scheduled for laboratory monitoring during chemotherapy
2. Screens should also be performed as clinically necessary on any patient complaining of muscle weakness, decrease in sensation, or change in function

The hand and foot filament sets for the Ambulatory Care Clinics may be obtained by calling 1-800-642-2477. The NHDP Rehabilitation Department staff are also available for consultation as necessary.

CONSULTANT SERVICES

- I. Due to the multi-faceted aspects of this disease, patients may need referral to the following ancillary medical services for complications. Not all consultant services will be needed in every case and some will be indicated only rarely. Consultation with NHDP staff is also available by calling 1-800-642-2477.
 - A. Physical Therapy
 - B. Occupational Therapy
 - C. Podiatry
 - D. Orthotics
 - E. Orthopedics
 - F. Ophthalmology
 - G. ENT
- II. Consultation with NHDP staff is also available by calling 1-800-642-2477.

CONTACT FOLLOW-UP

In the U.S., a Hansen's disease contact is identified as a person living in the same household with a new patient in the three year period prior to the diagnosis and the beginning of treatment. These contacts should be examined as follows:

- I. Contact examination
 - A. Exam of the entire skin
 - B. Nerve function assessment of the peripheral nerves, focusing primarily on the eyes, hands, and feet (See Appendix).
 - C. The contact exam should also include patient education on the disease, and what symptoms a contact should report to the health care provider.
 - D. An individual with symptoms of HD may be referred to one of the Outpatient HD Clinics or to the NHDP by physicians or healthcare agencies. These persons will be provided with the services required to rule out the diagnosis of HD as described above.

II. Follow-Up of Contacts

- A. Contacts of a paucibacillary case with a negative initial exam do not need follow-up as long as the patient has been educated about the symptoms of HD.
- B. In contacts of a multibacillary case, exams should be done annually for five years, including patient education about the disease and its symptoms
- C. The NHDP does not recommend chemoprophylaxis with dapsone or any other drug for contacts of patients.

REPORTING REQUIREMENTS

The NHDP maintains a National HD Registry in the U.S. for all patients diagnosed with Hansen's disease.. A Hansen's Disease Surveillance Form is required on all newly-diagnosed patients. The Form can be found on the NHDP website, www.hrsa.gov/hansens, and should be sent to NHDP as soon as the diagnosis is confirmed. The HD Surveillance Form should be mailed or faxed to:

NHDP
ATTN: Medical Records,
1770 Physicians Park Drive,
Baton Rouge, LA 70816
Fax: 225-756-3706

PATIENT EDUCATION

Appropriate treatment of a stigmatizing disease like HD involves more than merely prescribing medications. Many patients fear they will become severely disabled and will infect their families. They also fear social isolation if others become aware of their diagnosis. Awareness of these patient concerns at the time of diagnosis and during the course of treatment will more likely ensure patient compliance with treatment and achieve its objective, which is the prevention of deformity and disability.

REFERRALS TO NHDP

Physicians at the NHDP may authorize a referral to the NHDP on a case-by-case basis.

AMBULATORY CARE PROGRAM

The Ambulatory Care Program provides HD outpatient care through Outpatient Hansen's Disease Clinics located where most of the patients live in the U.S. and Puerto Rico. Services provided by these Clinics include diagnosis and treatment of HD and related conditions, laboratory monitoring, consultant services, patient and community education.

PRIVATE PHYSICIAN PROGRAM

HD medications can be provided to patients living in an area not served by an HD clinic through the NHDP. Their private physician can order the HD medications (dapsone, rifampin, clofazimine) from the NHDP at no charge to the patient. Consultant and biopsy processing services are also provided to the physician.

RESOURCES

- I. Resources available from the NHDP for HD are:
 - A. Consultation on treatment and management guidelines
 - B. Medications for HD: dapsone, rifampin, clofazimine
 - C. Processing biopsies for histopathology
 - D. HD and Foot Seminars for Physicians, Nurses, Occupational Therapists, Physical Therapists, Orthotists, and Podiatrists
 - E. NHDP Website-www.hrsa.gov/hansensdisease

Information regarding these services is available from the NHDP, 1770 Physicians Park Drive, Baton Rouge, LA, 70816, Phone: 800-642-2477; Fax: 225-756-3806.

- II. Other Resources
 - A. American Leprosy Missions
1 ALM Way
Greenville, SC 29601
Phone: 800-543-3131
 - B. IDEA (International Association for Integration, Dignity, And Economic Advancement)
U.S. Headquarters
P.O. Box 651
32 Fall Street-Suite A
Seneca Falls, NY 13148
Phone: 315-568-5838 Fax: 315-568-5891
E-mail: alaw@idealeprosydignity.org
 - C. Support for People with Hansen's Disease/Leprosy
Phone: 1-866-637-1525
Website: <http://www.hansensdisease.org>
E-mail: niholmes@hansensdisease.org

NHDP
Rev. 7/2012

FORMS AND PROCEDURES

APPENDIX A:	Hansen's Disease Monitors
APPENDIX B:	Peripheral Nerves
APPENDIX	Skin Biopsy Protocol for Submitting Specimens
APPENDIX D:	Skin Smears Skin Smears for Acid-Fast Bacilli Procedure for Obtaining Smears Skin Smear/Biopsy Chart Staining of Skin Smears Microscopic Examination of Skin Smears
APPENDIX E:	Hand and Foot Screens Standards for Performance of the Hand Screen Hand Screen Instructions Hand Screen Record Standards for Performance of the Foot Screen Foot Screen Encounter Form Foot Screen Record WHO Grading of Disabilities Hands and Feet
APPENDIX F:	Hansen's Disease Medication Chart English Spanish
APPENDIX G:	Surveillance Form Instructions for Surveillance Form HD Surveillance Form
APPENDIX H:	Hansen's Disease Outpatient Clinic Listing
APPENDIX I:	Hansen's Disease Outpatient Clinic Listing

APPENDIX

Hansen's Disease Monitors

The Hansen's disease (HD) monitors are a system of assessment which includes a visual inspection and assessment of motor function of the eyes, hands, and feet of a patient with HD. These procedures can be used to teach patients about prevention of complications.

1. Visual Inspection**a. Eyes**

1. Examine the eyes for inflammation
2. Check the pupil size, shape, and reaction to light
3. Ask the patient to close their eyes and check for incomplete closure

b. Hands

1. Inspect the palms and dorsum of the hands for dry skin
2. Check for muscle atrophy and injuries

c. Feet

1. Inspect for dry skin, erythema, calluses, and injuries
2. Check socks and shoe wear for signs of drainage from ulcers or injuries

2. Motor Function Assessment

These assessments should be done with the application of resistance by the examiner, otherwise early signs of weakness may be missed. (See attachment)

3. Shoewear Assessment for Insensitive Feet

- a. Extra-depth shoes with removable insoles
- b. Rounded or square toe box
- c. Leather upper
- d. A half-inch length beyond longest toe
- e. No seams at the toe
- f. Soft wedge sole

A patient with a positive eye exam should be evaluated by an ophthalmologist; hand and foot problems need follow-up with a hand or foot screen and referred as necessary.

HANSEN'S DISEASE MONITORS

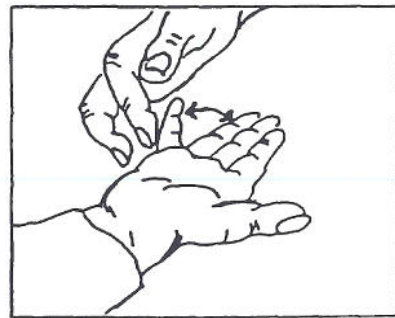
FACIAL NERVE

Have patient close eyes as in sleep. Look for incomplete closure of eyelids.



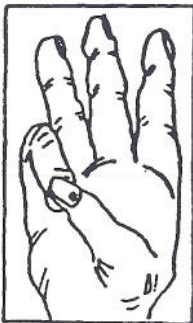
ULNAR NERVE

Have patient abduct little finger against resistance applied by examiner.



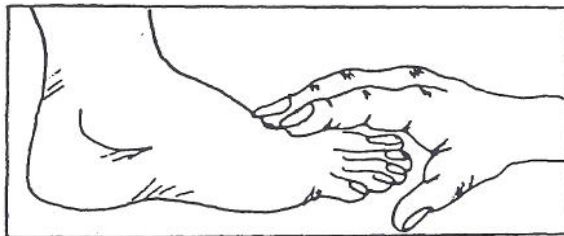
MEDIAN & ULNAR NERVES

Have patient approximate little finger and thumb with hand in prone position.



PERONEAL NERVE

Ask the patient to bring foot up. Apply resistance when foot is up. There will be weakness or paralysis when patient is unable to resist the downward movement that is applied to the foot.



These assessments are to be done with application of resistance by examiner; otherwise early signs of weakness may be missed. A patient with a positive eye exam should be evaluated by an ophthalmologist. Positive hand or foot assessments shall be further evaluated through a hand or foot screen and referred.

PERIPHERAL NERVES



Greater auricular-with the patient's head turned to one side, palpate the nerve as it stretches across the sternomastoid muscle.



Ulnar-palpate above the ulnar groove.



Radial cutaneous-palpate at the lateral border of the radius proximal to the wrist joint.



Posterior tibial-posteriorly and inferiorly to the medial malleolus.



Common peroneal-palpate the popliteal fossa just medial to the biceps femoris tendon, and around the neck of the fibula.

SKIN BIOPSY

A proper site is the single most important factor in the skin biopsy to be evaluated for leprosy. The pathologist will be unable to make a definite diagnosis if bacilli cannot be demonstrated by means of the biopsy. A general rule is that the biopsy should be taken entirely within the lesion, preferably from the active margin if there is one; this is especially important in the non-lepromatous forms of leprosy. There is no necessity to include any normal tissue in the biopsy. When no definite lesion can be found, the site for biopsy should be guided by information from skin scrapings and clinical findings such as decreased sensation and decreased sweating.

The skin biopsy should be made with a biopsy punch or by surgical excision. In all instances, the biopsy should be deep enough to include subcutaneous fat; this depth of biopsy is very important, for often the most prominently involved nerves will be found in the upper portion of the subcutaneous tissue. A 4 mm or larger biopsy punch should be used; a 2 or 3 mm punch biopsy can be made on the face, if necessary. Surgical excision is made 1 cm by 3 mm, with a cold knife; removal of specimens by cautery is to be entirely avoided. A proper fixative should be employed for specimen fixation and transfer; 10% neutral buffered formalin is used routinely. At least five volumes of fixative per volume of tissue should be used.

For his to pathological consultation, at no charge, mail specimens in 10% neutral buffered formalin to:

National Hansen=s Disease Programs
Attention: Clinical Laboratory
1770 Physicians Park Drive
Baton Rouge, Louisiana 70816

For questions regarding these procedures, please call 1-800-642-2477.

PROTOCOL FOR SUBMITTING SPECIMENS FOR HISTOLOGICAL EVALUATION OF HANSEN'S DISEASE

National Hansen's Disease Programs
Baton Rouge, Louisiana

The following are the requirements needed before sending a biopsy for routine histological evaluation:

1. A biopsy collected with a 4 – 5 mm punch (2 mm if on face) or surgical excision, which should be deep enough to include subcutaneous fat. This depth is important because often the most prominently involved nerves will be found in the upper portion of the subcutaneous fat. As a general rule, the biopsy should be taken entirely within the lesion, preferably from the active margin if there is one.
2. Place in 10% buffered formalin, at least 5 volumes of fixative per volume of tissue. Label container with patient's name and biopsy site.
3. A brief clinical history including number of lesions, changes in sensation, previous diagnosis and present clinical impressions.
4. The patient's name, sex, race and social security number if available.
5. The patient's date of birth.

6. The submitting doctor's name and the address where the report is to be sent.
7. Send biopsy in leak-proof container.

The following specimens may also be submitted for evaluation (listed in order of preference):

1. Paraffin blocks.
2. Slides of unstained sections - preferably at least 4 slides.
3. Stained slides to include H&E and Fite.

Specimens should be placed in protected mailing containers such as screw-cap cardboard cylinders or padded mailing envelopes to prevent damage.

Specimens are then sent to:

National Hansen's Disease Programs
Clinical Laboratory
1770 Physicians Park Drive
Baton Rouge, LA 70816
Attn: George Reed or Steve Keas
Phone: 1-800-642-2477

SKIN SMEARS FOR ACID-FAST BACILLI

PURPOSE:

The skin smear is a valuable, cost-effective tool in the routine management of the Hansen=s disease patient. The smear is a means of estimating the number of acid-fast bacteria present, reported as the bacterial index (BI), and is important in determining the type and severity of disease as well as assessing the response to treatment.

GENERAL:

1. Initial skin smears are usually taken from 6 Aroutine sites@ (both earlobes, elbows, and knees) as well as several typical lesions from the patient.

Repeat smears are obtained from 3 to 4 of the most active sites previously tested to evaluate progress.

2. The time interval between repeat smears is determined by the physician but in general, annual smears are adequate for monitoring response to treatment and during the follow-up period to detect any evidence of relapse.

3. They may be sent in protective mailers to:

National Hansen=s Disease Programs
Attention: Clinical Laboratory - Skin Smears
1770 Physicians Park Drive
Baton Rouge, Louisiana 70816
Phone: (225) 756-3733


PROCEDURE FOR OBTAINING SMEARS:


1. Universal precautions should be observed in obtaining skin smears.
2. All microscopic slides on which skin smears are made should be precleaned in 70% alcohol, acetone, or alcohol-acetone to remove amorphous debris. The slides are wiped dry with a clean hand towel. Blades that are used in smear taking are likewise cleaned.
3. The skin is cleansed with 70% alcohol and air dried or wiped dry with cotton. (Zepharin tends to make the skin too slippery and is not recommended.)
4. A fold of skin is made relatively avascular by pinching. If the skin cannot be grasped by pinching, it can be compressed. A surgeon's glove may aid in grasping.
5. Local anesthesia is generally unnecessary. (If there is not adequate decrease in sensation,


obtain local anesthesia with 1% Xylocaine, or Ethyl Chloride spray can be carefully applied.) The compression of the skin by pinching aids in the anesthesia.

6. An incision 3-5 mm long and 2-3 mm deep is made with an alcohol-cleansed single-edge razor blade or a scalpel with a #15 Bard-Parker blade may also be used. **The blade or scalpel should be used for only one site and then discarded.** Mild pressure to maintain relative avascularity is continuously applied to the area until an adequate smear has been obtained.
7. A small amount of blood does not interfere with the reading, but large amounts should be avoided and can usually be controlled by the amount of pressure of the pinch. If excessive bleeding occurs, it can be wiped away with a cotton swab.
8. After the incision is made, and before the blade is withdrawn, the inner surface of the wound is scraped with the blade held at a right angle to the incision. Upon scraping, tissue fluid and dermal tissue are obtained.
9. The material is transferred to the cleaned microscope slide. A moderately thick smear, with a visible uniform opacity is made. The smear is made in a circular manner on the slide, **no larger than a pencil eraser (5-7 mm) in diameter**, beginning peripherally and ending in the center, leaving a central "button" (2-4 mm) which can be easily focused upon with the microscope. Slides should be properly labeled as shown in the sample diagram for 3 routine sites.

Name	
1. R -knee	
2 .R-elbow	
3. R - ear	
Date	

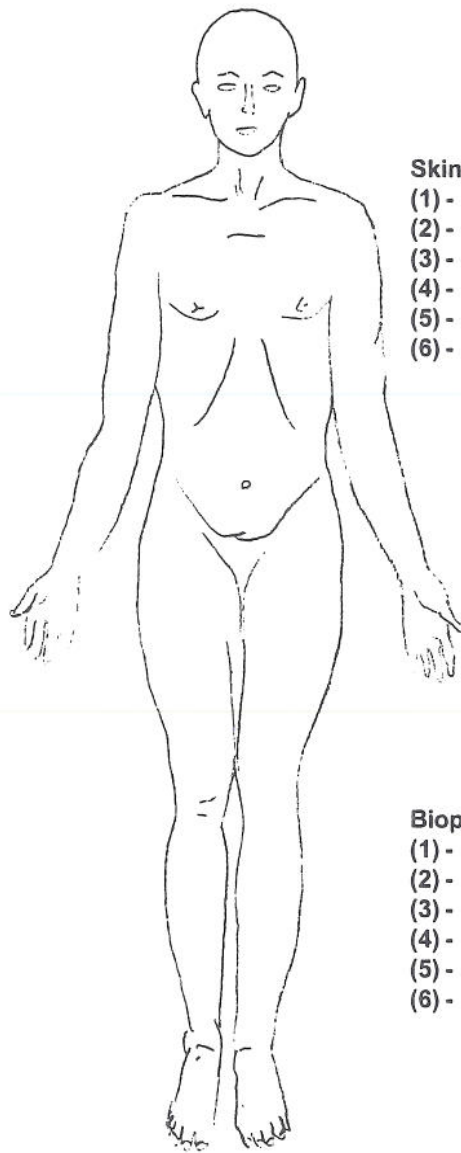
3


2


1


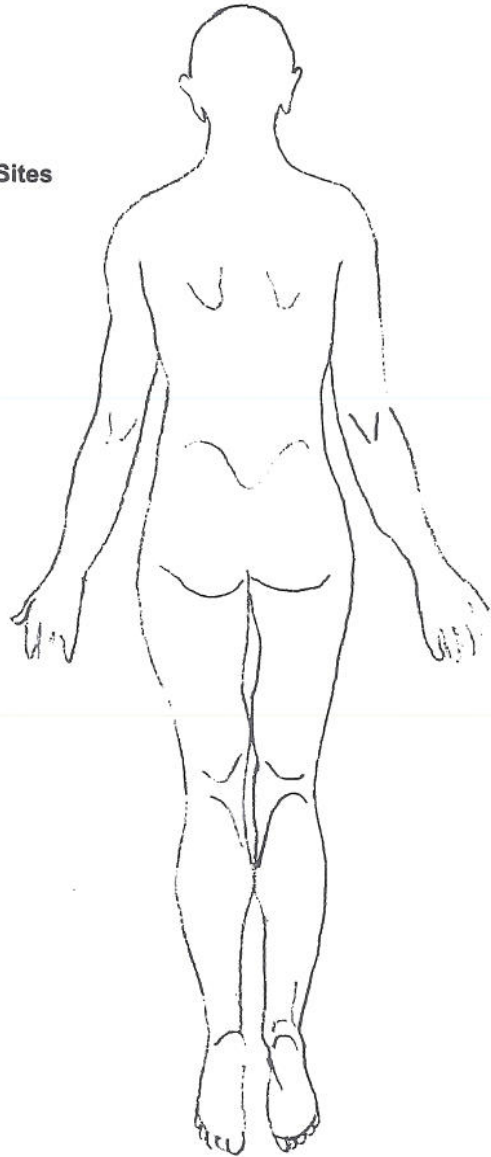
10. Slides should be air-dried and **NEVER** heat fixed.
11. A Band Aid is generally sufficient to protect the smear site.
12. A single technician takes all smears to provide for more uniform and consistent results.
13. The smears may be sent to the National Hansen's Disease Programs for reading.
14. A chart to diagram sites of the skin smears or biopsy is attached to "Skin Biopsy" in the appendix. It can be copied for your convenience.

NATIONAL HANSEN'S DISEASE PROGRAMS		SKIN SMEAR / BIOPSY CHART	DATE: _____
Patient's Name (Last, First, Middle): _____			HD ID No: _____
Date of Birth: _____	Social Security No.: _____	Phone results to: _____	



Skin Smear Sites

- (1) -
- (2) -
- (3) -
- (4) -
- (5) -
- (6) -



Biopsy Sites

- (1) -
- (2) -
- (3) -
- (4) -
- (5) -
- (6) -

Private Physician:

Name: _____

Address: _____

STAINING OF SKIN SMEARS

1. Dry the slide with smear at room temperature. **DO NOT HEAT FIX.**
2. Place slides on a staining rack and flood with 10% formalin for 15 minutes for fixation.
3. Rinse with tap water.
4. Flood slides with Ziehl-Neelsen carbol-fuchsin for twenty minutes. (Always filter stain before each use.)
5. Rinse with tap water.
6. Decolorize with 2% acid alcohol for 1 minute.
7. Rinse slides thoroughly with tap water.
8. Counterstain with alkaline methylene blue for 30 seconds to 1 minute.
9. Rinse with tap water and air dry.

NOTE: Positive and negative control slides must be used each day for quality control purposes.

Z-N Carbol Fuchsin Stain:

Basic fuchsin.....1.0 gm.
Phenol crystals.....5.0 gms.
95% ethanol.....10.0 mls.
Water, to make.....100.0 mls.

Acid alcohol:

Conc. HCl.....2.0 mls.
95% ethanol.....98.0 mls.

Alkaline Methylene Blue:

KOH (10%).....10.0 mls.
Methylene blue..... 0.35 gms.
95% ethanol..... 16.0 mls.
Water to make..... 100.0 mls.

MICROSCOPIC EXAMINATION OF SKIN SMEARS:

The stained smears are examined with a quality microscope using the oil immersion objective (x100) to determine the total number of bacilli. The same individual should read all smears for the purpose of consistency. The smear will have similar numbers of bacilli throughout, however, four separate quadrants of the smear are examined and averaged to establish the Bacterial Index (BI).

REPORTING THE BACTERIAL INDEX (BI):

The results are reported on a 0 to 6 + semi-logarithmic scale using a descriptive phrase or numerical code. This is an indicator of the total bacillary load of the patient. It falls about 1 point per year during effective treatment as dead bacilli undergo lysis and are absorbed.

Very Numerous (+6)	-	over 1000 bacilli per oil immersion field.
Numerous (+5)	-	100 to 1000 bacilli per oil immersion field.
Moderate (+4)	-	10 to 100 bacilli per oil immersion field.
Few (+3)	-	1 to 10 bacilli per oil immersion field.
Very few (+2)	-	1 to 10 bacilli per 10 fields.
Rare (+1)	-	1 to 10 bacilli per 100 fields.
None found (NF)	-	No AFB seen on entire site.

STANDARDS FOR PERFORMANCE OF HAND SCREEN

The hand screen is intended to record the baseline and risk assessment of patients requiring acute care, or receiving health education, and it helps identify patients in need of treatment to prevent progressive nerve damage (decrease in sensory and muscle function). The majority of patients may not have sensory or muscle involvement of the hands or will have long-standing involvement that is not changing.

Long standing sensory and muscle loss that is unchanging does not need treatment of the nerve, however, the patient may benefit from deformity prevention techniques (splinting/education/adaptive devices).

The sensory testing device used with the Hand Screen is a set of five (5) calibrated nylon filaments mounted on a small rod, which measures levels of coetaneous touch and pressure on a scale of 2.83 to 6.65. The normal threshold level is 2.83.

WHEN TO PERFORM THE SCREEN

- A baseline hand screen is performed on all new patients at the time of diagnosis.
- Screens are performed on a quarterly basis as patients are scheduled for laboratory monitoring during chemotherapy for HD.
- Screens shall also be performed as clinically necessary on any patient complaining of muscle weakness, decrease in sensation, or change in function.

PATIENTS WITH NERVE CHANGES:

Patients whose sensory and muscle function has deteriorated over the last 6-12 months are experiencing reaction in the nerves; these are considered “acute” nerves.

Patients with “acute” nerves need immediate attention in order to prevent progression in nerve involvement, and examination by the physician for treatment of the nerve with corticosteroids or other anti-inflammatory agents.

Referral to an occupational therapist may be warranted for patient education in reducing stress on the acute nerve, protection of the nerve, or temporary immobilization.

HAND SCREEN INSTRUCTIONS

PATIENT DATA:

Use middle initial or middle name if available.

Use patient's social security number.

SECTION I SENSORY TEST:

- A. Perform the test with the patient's eyes closed or averted.
- B. Select the sites to be tested as indicated on the Hand Screen form.
- C. Use Filament #1, the lightest, first. If equates to normal sensation (0.05 gram).
- D. Apply the filament slowly to bending (just before bending to the heaviest), hold 1.5 seconds, remove slowly.



- E. Apply the filament three times (slowly) in succession and record if the patient feels any of the three applications.
- F. If the first filament is not felt, proceed to the next heavier filament, repeating the process until a filament is felt.
- G. Record the number of the filament first felt in the appropriate blank, next to the appropriate number. If no filament is felt, put a zero in the blank to indicate the test was completed for that site, but the patient did not respond.
- H. Do not allow the filament to slide across the skin.
- I. Ask the patient to reply "yes" when the filament is felt.
- J. Apply the filament along the margin of and NOT on an ulcer site, callous or scar.

SECTION II SKIN INSPECTION:

Use initials indicated on form to mark hand map and for lesions and observations made of the condition of the patient's hands.

SECTION III MUSCLE TESTING:

Results of muscle testing are graded as strong, weak, or paralyzed.

Strong – Normal ROM and full resistance

Weak – Reduced ROM with reduced or no resistance

Paralyzed – No contraction palpable.

1. Abduction of index finger (ulnar).
Index finger should be abducted with some slight flexion in the knuckle joint, with all other joints straight. Apply resistance at the base of the index finger. Thumb of supporting hand can palpate for possible muscle contraction.
2. Abduction of little finger (ulnar).
Ask patient to move little finger out and slightly up, palm side up, keeping all the joints of the finger straight. Apply resistance at the base of the little finger. Fingers of your supporting hand will be able to palpate for possible muscle contraction.
3. Abduction of the thumb (median).
Move thumb away from palm of hand at right angles to the plane of the palm of the hand. Resistance is applied at the base of the thumb, pushing it in to the index finger.
4. Opposition of the thumb (median).
Have patient make ring with thumb and little finger, try to push thumb out.
5. Wrist extension (radial).
Ask the patient to make a fist, and try to push the wrist down on the radial side. If weakness is present, patient may not be able to resist or wrist may deviate to unaffected side.

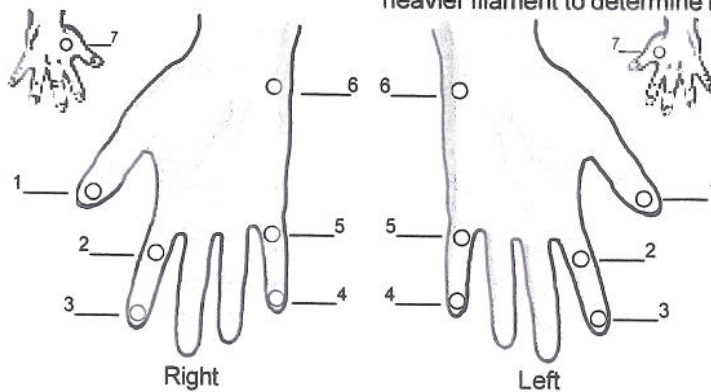
SECTION IV PERIPHERAL NERVE RISK:

Weakness or paralysis is usually not present wherever normal sensation or sweating is found. Loss of sensation and weakness may occur at the same time or sometimes months or years later.

Peripheral nerve involvement of short duration is more apt to be responsive to treatment. Acute nerve involvement may be successfully minimized or reversed by treatment with corticosteroids, anti-inflammatory agents, immobilization,

PROGRAM NAME:		HAND SCREEN RECORD		Date:
Patient's Name (Last, First, Middle):			SS No.	Reaction: Type I ____ Type II ____
Patient's File No.	Medications:	Date of Disease Onset	Classification	Initial ____ F/U ____

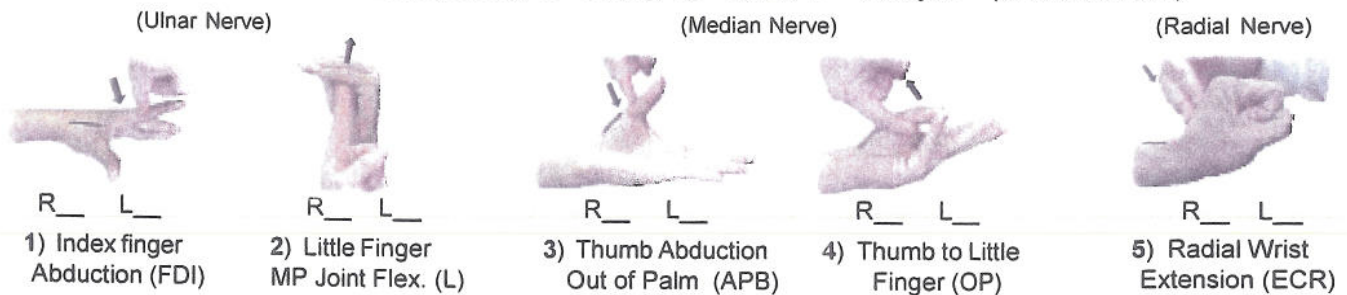
Section I. **SENSORY TESTING:** Use first filament (A) at site indicated (*apply three times*). If no response, use next heavier filament to determine level of loss.



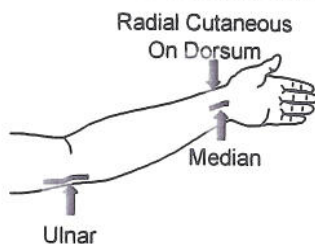
Filament	Force, gms	Interpretation	(Grade Pts.)
A Green (2.83)	0.05	Normal	(5)
B Blue (3.61)	0.20	Residual Texture	(4)
C Purple (4.31)	2.00	Residual Protective Sensation	(3)
D Red (4.56)	4.00	Loss of Protective Sensation	(2)
E Orange (6.65)	300.00	Residual Deep Pressure	(1)

Section II. **SKIN INSPECTION:** Draw and label (*above*): W - Wound, C - Callus, S - Swelling, R - Redness, D - Dryness, T - Temperature, M - Missing, J - Contracture, O - Other

Section III. **MUSCLE TESTING:** Mark (*below*): S = Strong, W = Weak, P = Paralysis (*or Grade 5 to 0*)



Section IV. **PERIPHERAL NERVE RISK:** Mark: U, M, R (*or combination*)



- | | |
|---|---------------|
| 1) Enlarged or swollen nerve | R ____ L ____ |
| 2) Tender / painful on stretch or compression | R ____ L ____ |
| 3) Sensory change in the last 12 months | R ____ L ____ |
| 4) Muscle change in the last 12 months | R ____ L ____ |

High Risk (*acute or changing nerve*): Yes ____ No ____
(*refer to physician/therapist*)

Section V. **DEFORMITY RISK:** (*Check if present*)

- | | | | |
|---|---------------|---|---------------|
| 1) Loss of Protective Sensation | R ____ L ____ | 4) Injuries (<i>wounds, blisters, etc.</i>) | R ____ L ____ |
| 2) Clawed but Mobile Hand | R ____ L ____ | 5) Contracted or Stiff Joints | R ____ L ____ |
| 3) Fingertip Absorption (Mild ____ Severe ____) | R ____ L ____ | 6) Wrist Drop (<i>radial nerve</i>) | R ____ L ____ |

High Risk (*any of the above*): Yes ____ No ____
(*refer for appropriate treatment*)

Has there been a change in the hand since any previous exam? Yes ____ No ____

Examined by: _____

wrapping to keep it warm, or possibly surgery (nerve transfer).

Classification is graded on a scale of 1 to 4.

Risk Category 1:

A patient in this category may need to be followed for the possibility of further problems.

Risk Category 2:

Tender nerve on stretch or compression, with the ulnar nerve in the area of the olecranon process in the elbow. May be tender on flexion of arm or if pressure applied to area. To palpate for an enlarged nerve, use the four fingers of one hand and gently roll the nerve under them. A normal nerve is slightly thick or may not be palpable at all. A hard, sclerosed nerve is abnormal.

Risk Category 3:

Sensory change in the last 12 months.

Risk Category 4:

Muscle change in the last 12 months.

Section V

DEFORMITY RISK:

This is classified from a range of 1 to 5, which lists types of disability which may be present in a patient.

STANDARDS FOR PERFORMANCE OF THE FOOT SCREEN

The initial foot screen is intended to record the baseline status of patient subjective data and clinical signs and symptoms of neurological impairment. The foot screen evaluates history or presence of plantar ulceration, strength of specific muscles, plantar foot sensation, and deformities which can place the foot at risk of injury. After the initial evaluation, screens are performed annually to monitor or pick up any undetected changes by the patient and are indicated more often if the patient perceives any change in sensory, motor or functional status. The screen is a tool to bring up any treatment issues such as wound, callus, and toenail care, footwear and orthotic needs.

The Screen is also used to place the patient in a Risk Category. The foot screen assessment section or risk category serves as a guideline for routine foot checks. This check up is for monitoring and trimming plantar callus and toenails and for checking on appropriateness of patient footwear and orthotics.

The sensory testing device used with the Foot Screen is a nylon filament mounted on a holder and is designed to deliver a 10 gram force when properly applied. Our research has shown that a patient who can feel the 10 gram filament in the selected sites will not develop ulcers.

Rating categories are based on the objective data and are defined as follows:

- Category 0 - No Loss of Protective Sensation (LOPS)
- Category 1 - LOPS but no deformity
- Category 2 - LOPS and deformity
- Category 3 - LOPS and history of ulceration
- Category 4 - Charcot foot

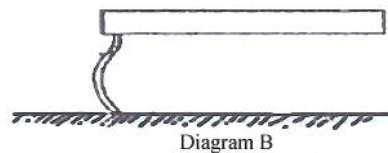
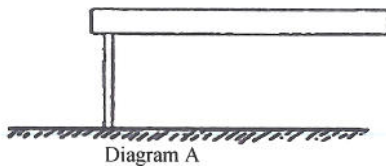
WHEN TO PERFORM THE SCREEN

- A baseline hand screen is performed on all new patients at the time of diagnosis.
- Screens are performed on a quarterly basis as patients are scheduled for laboratory monitoring during chemotherapy for HD.
- Screens shall also be performed as clinically necessary on any patient complaining of muscle weakness, decrease in sensation, or change in function.

FOOT SCREEN ENCOUNTER FORM

Instructions for sensory testing on the foot:

1. Use the 10 gram filament provided to test sensation.
2. Select the sites to be tested based on the Foot Screening Form.
3. Apply the filament perpendicular to the skin's surface. (See diagram A)
4. The approach, skin contact and departure of the filament should be approximately 1 ½ seconds duration.
5. Apply sufficient force to cause the filament to bend (See diagram B)



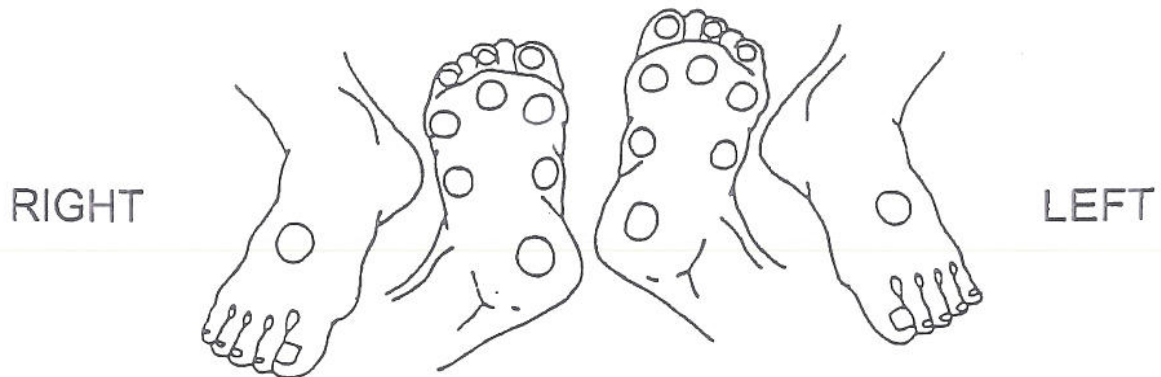
6. Do not allow the filament to slide across the skin or make repetitive contact at the test site.
7. Randomize the selection of test sites and time between successive tests to reduce the potential for patient guessing.
8. Ask the patient to respond "yes" when the filament is felt.
9. Apply the filament along the perimeter of and NOT on an ulcer site, callous, scar or necrotic tissue.
10. Foot screens are performed annually. If the patient has symptoms of neuritis, e.g., burning on the soles of the feet, pain in the lower extremities, or is on treatment for neuritis, the foot screen should be done more frequently to monitor progress or to refer to the clinician.
11. A copy of the Foot Screen must be sent to the NHDP.

HD CLINIC		FOOT SCREEN RECORD		DATE:
PATIENT'S NAME (Last, First, Middle)			SS#	REACTION: TYPE I _____ TYPE II _____
PATIENT'S FILE NO:	MEDICATIONS:	DATE OF HD ONSET:	CLASSIFICATION:	
LOWER EXTREMITY SURGERY:			TYPE OF WORK USUALLY DONE:	

Fill in the following blanks with and R, L, or B to indicate positive findings on the right, left or both feet.

Has there been a change in the foot since last evaluation?	Yes _____ No _____
Is there a foot ulcer now or history of foot ulcer?	Yes _____ No _____
Does the foot have an abnormal shape?	Yes _____ No _____
Is there weakness in the ankle or foot?	Yes _____ No _____
Are the nails thick, too long or ingrown?	Yes _____ No _____

Label: Sensory level with a "+" in the circled areas of the foot if the patient can feel the 10 gram (5.07 Semmes-Weinstein) nylon filament and "-" if he/she can not feel the 10 gram filament.



Clinical Appearance Of Skin:

Does the patient use footwear appropriate for his/her category? Yes _____ No _____

RISK CATEGORY:

- ___ 0 No protective sensory loss
- ___ 1 Loss of protective sensation (no deformity, or plantar ulcer history).
- ___ 2 Loss of protective sensation and deformity (no plantar ulcer history).
- ___ 3 History of plantar ulcer.

PATIENT EDUCATION: Skin care, inspection, footwear

REFERRALS: _____

Date of Next Evaluation:








- Category 0 – One Year _____
- Category 1 – One Year _____
- Category 2 – Six Months _____
- Category 3 – One – Three Months _____

WHO GRADING OF DISABILITIES HANDS AND FEET

- Grade 0: No anesthesia, visible deformity, or damage
- Grade 1: Anesthesia present, but no visible deformity or damage
- Grade 2: Visible deformity or damage present








Each hand and foot should be assessed and graded separately. Damage in this context includes ulceration, shortening, disorganization, stiffness, or loss of part or all of the hand or foot. If any disability found in the patient is due to causes other than leprosy, this fact should be noted.

HANSEN'S DISEASE MEDICATIONS

DRUG NAME	DRUG DOSAGE	HOW TO TAKE **	COMMON SIDE EFFECTS
RIFAMPIN 300 mg 	TAKE AS DIRECTED BY PHYSICIAN DIRECTIONS:	TAKE ON AN EMPTY STOMACH 1 HOUR BEFORE MEALS OR 2 HOURS AFTER MEALS	May color urine, sweat, sputum, tears red. May upset stomach or give you flu-like symptoms. Often interferes with other medicine. Inform us if you are taking any new medicines, even birth control pills.
DAPSONE 25 mg  100 mg 	TAKE AS DIRECTED BY PHYSICIAN DIRECTIONS:	CAN TAKE ON EMPTY OR FULL STOMACH	May cause muscles weakness or give you a sore throat and fever. If this happens, stop the drug and call HD clinic nurse.
CLOFAZIMINE 50 mg 	TAKE AS DIRECTED BY PHYSICIAN DIRECTIONS:	TAKE WITH FOOD	May color skin, urine, sweat, sputum or whites of eyes brown. Skin may become dry; use lotion on skin at least twice a day.
PREDNISONE <i>(drug may vary in colors / sizes)</i> 5 mg  20 mg 	TAKE AS DIRECTED BY PHYSICIAN DIRECTIONS:	TAKE WITH FOOD	<u>Drug must be gradually decreased.</u> NEVER ABRUPTLY STOP DRUG! Take as directed by MD. May have increased appetite or increased energy.
MINOCYCLINE 100 mg 	TAKE AS DIRECTED BY PHYSICIAN DIRECTIONS:	MAY BE TAKEN ON AN EMPTY OR FULL STOMACH DO NOT TAKE ANTACIDS OR IRON SUPPLEMENTS WHILE TAKING THIS MEDICINE	Wear sunscreen in sunlight. Dizziness can occur. Stop medicine if hives develop. Women can get yeast infections. Call HD nurse if you develop any symptoms of a yeast infection: Vaginal discharge or vaginal itching/burning.

** NOTE: All medications should be taken with a full glass of water.

MEDICINAS PARA LA ENFERMEDAD DE HANSEN

DROGA	DOSIS	COMO SE TOMA**	EFECTOS SECUNDARIOS
RIFAMPIN 300 mg 	TOME COMO INDICADO POR SU MEDICO DIRECCIONES:	TOME EN AYUNAS 1 HORA ANTES DE COMER O 2 HORAS DESPUES DE COMER NO TOME ANTACIDOS (TUMS, ect) Durante una hora de haberse tomado	Puede enrojecer la orina, esputo, o la orina. Puede irritar el estomago o causarle sintomas de parecidos a los de la gripa. Puede interferir con otras medicinas. Avisenos si es que esta tomando cualquier medicina incluyendo pastillas anticonceptivas.
DAPSONE 25 mg  100 mg 	TOME COMO INDICADO POR SU MEDICO DIRECCIONES:	TOME EN AYUNAS O DESPUES DE COMER	Puede provocar debilidad muscular, dolor de garganta y fiebre. En dado caso, descontinúe la droga y llame a la enfermera de la clinica HD
CLOFAZIMINE 50 mg 	TOME COMO INDICADO POR SU MEDICO DIRECCIONES:	TOME CON COMIDA	Puede alterar el color de la piel, orina, sudor, y esputo, o la parte blanca de los ojos. Puede resecarle la piel. Use una locion para la piel por lo menos dos veces al dia.
PREDNISONE <i>(puede variar de color/tamano)</i> 5 mg  20 mg 	TOME COMO INDICADO POR SU MEDICO DIRECCIONES:	TOME CON COMIDA	<u>Se debe disminuir gradualmente la dosis de esta droga. NO SE DEBE DETENER BRUSCAMENTE!</u> Tome como le indique su DOCTOR. Puede aumentar su apetito o energia.
MINOCYCLINE 100 mg 	TOME COMO INDICADO POR SU MEDICO DIRECCIONES:	SE PUEDE TOMAR EN AYUNAS O DESPUES DE COMER NO TOME ANTACIDOS NI SUPLEMENTOS DE HIERRO DURANTE DOS HORAS ANTES O DESPUES DE TOMAR ESTA MEDICINA	Aplíquese bloqueador de sol. Puede causar mareos. Detenga la medicina si le salen ronchas. Las mujeres pueden sufrir infecciones de ciertos hongos. Llame a la enfermera de la clinica HD si sufre cualquier sintoma de infeccion: flujo vaginal, comezon/ardor.

** NOTE Tome toda medicina con un vaso de agua

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 <div style="text-align: center;">□ □</div>		2 Date of Report <div style="text-align: center;">Mo. Day Yr. □ □ □ □ □ □</div>		3 Social Security Number (optional) <div style="text-align: center;">- - - - -</div>																																																																									
4 Patient Name: (Last) (First) (Middle)																																																																													
5 Present Address: Street City County State Zip																																																																													
6 Place of Birth: State County Country			7 Date of Birth: Mo. Day Yr. □ □ □ □ □ □		Sex: <input type="checkbox"/> Male <input type="checkbox"/> Female																																																																								
8 Race/Ethnicity: <input type="checkbox"/> White, Not Hispanic <input type="checkbox"/> White, Hispanic <input type="checkbox"/> American Indian, Alaska Native <input type="checkbox"/> Indian, Middle Eastern <input type="checkbox"/> Black, Not Hispanic <input type="checkbox"/> Black, Hispanic <input type="checkbox"/> Asian, Pacific Islander <input type="checkbox"/> Not Specified																																																																													
9 Date Entered U.S.: Mo. Yr. □ □ □ □		10 Date of Onset of Symptoms: Mo. Yr. □ □ □ □		11 Date Leprosy First Diagnosed: Mo. Yr. □ □ □ □																																																																									
12 Initial Diagnosis in: <input type="checkbox"/> U.S. <input type="checkbox"/> Outside U.S.																																																																													
13 Type of Leprosy: (ICD-9-CM Code) (NHDP Clinic physicians: Please circle specific classification, if possible) <input type="checkbox"/> Lepromatous (030.0 - LL, BL) <input type="checkbox"/> Indeterminate (030.2 - IN) <input type="checkbox"/> Other Specified Leprosy (030.8) <input type="checkbox"/> Tuberculoid (030.1 - TT, BT) <input type="checkbox"/> Borderline (030.3 - BB) <input type="checkbox"/> Leprosy, Unspecified (030.9)																																																																													
14 Diagnosis of Disease: Was biopsy performed in U.S. <input type="checkbox"/> Yes <input type="checkbox"/> No Date ____ / ____ / ____ Result _____ Skin Smear <input type="checkbox"/> Yes <input type="checkbox"/> No Date ____ / ____ / ____ BI: Positive _____ Negative _____			15 List all places in the U.S.A. and all foreign countries a PATIENT resided (Including Military Service) BEFORE leprosy was diagnosed.																																																																										
			<table border="1" style="width: 100%; border-collapse: collapse;"> <thead> <tr> <th style="text-align: center;">TOWN</th> <th style="text-align: center;">COUNTY</th> <th style="text-align: center;">STATE</th> <th style="text-align: center;">COUNTRY</th> <th colspan="2" style="text-align: center;">INCLUSIVE DATES</th> </tr> <tr> <th colspan="4"></th> <th style="text-align: center;">From Mo./Yr.</th> <th style="text-align: center;">To Mo./Yr.</th> </tr> </thead> <tbody> <tr><td> </td><td> </td><td> </td><td> </td><td> </td><td> </td></tr> <tr><td> </td><td> </td><td> </td><td> </td><td> </td><td> </td></tr> <tr><td> </td><td> </td><td> </td><td> </td><td> </td><td> </td></tr> <tr><td> </td><td> </td><td> </td><td> </td><td> </td><td> </td></tr> <tr><td> </td><td> </td><td> </td><td> </td><td> </td><td> </td></tr> <tr><td> </td><td> </td><td> </td><td> </td><td> </td><td> </td></tr> <tr><td> </td><td> </td><td> </td><td> </td><td> </td><td> </td></tr> <tr><td> </td><td> </td><td> </td><td> </td><td> </td><td> </td></tr> <tr><td> </td><td> </td><td> </td><td> </td><td> </td><td> </td></tr> <tr><td> </td><td> </td><td> </td><td> </td><td> </td><td> </td></tr> </tbody> </table>			TOWN	COUNTY	STATE	COUNTRY	INCLUSIVE DATES						From Mo./Yr.	To Mo./Yr.																																																												
TOWN	COUNTY	STATE	COUNTRY	INCLUSIVE DATES																																																																									
				From Mo./Yr.	To Mo./Yr.																																																																								
16 Disability: Hands Feet Eye Yes / No Yes / No Sensory Loss <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Lagophthalmos? Deformity <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/>																																																																													
17 Current Household Contacts: Name/Relationship 1 _____ 2 _____ 3 _____ 4 _____ 5 _____			18 Current Treatment for Leprosy: (check all that apply) Date Treatment Started: ____ / ____ Mo. Yr. <input type="checkbox"/> Dapsone <input type="checkbox"/> Rifampin <input type="checkbox"/> Clofazimine <input type="checkbox"/> Other (list) _____ _____ _____																																																																										

19 Name and Address of Physician: _____
 Investigator: _____

This form may be FAXED to NHDP at (225) 756-3706
 A copy of this form should be sent to your local or state health department.

HD CLINIC	CHANGE OF INFORMATION	DATE
Last Name, First name, Middle Initial		
Date of Birth:	Social Security No.	

☐ Check box if there are any changes in the above information.

In accordance with the national Hansen's Disease Program Policy, the following change is reported:

The above patient has:

☐ Relocated To:

City State Zip

Hansen's Disease Clinic

☐ Left the Country

☐ Deceased: _____
Date

HANSEN'S DISEASE CLINICS***National Hansen's Disease Programs
Ambulatory Care Program***Webpage: www.hrsa.gov/hansensdisease

Toll Free Phone Number: 800-642-2477

ATLANTA HD CLINICEmory MidTown Hospital
550 Peachtree Street NE
7th Floor MOT

Atlanta, GA 30308

PH: (404) 686-5885

Fax: (404) 686-4508

Primary Physicians – Dr. Jessica Fairley/Dr. Phyllis Kozarsky

email: jessica.fairley@emory.eduemail: pkozars@emory.edu

PH: (404) 686-5885

Public Health Nurse: Roberta Dismukes, RN

email: roberta.dismukes@emoryhealthcare.org

PH: (404) 320-6662

PH: (404) 686-7668

BOSTON HD CLINIC

Lahey Medical Center

41 Mall Road

Burlington, MA 01805

PH: (781) 744-5670

Fax: (781) 744-5687

Primary Physician - Dr. Samuel Moschella

email: samuel.l.moschella@lahey.org

Public Health Nurse - Ms. Stephanie Burns, RN, D.N.C.

email: stephanie.a.burns@lahey.org**CHICAGO HD CLINIC**

University of Illinois

College of Medicine at Chicago

Department of Dermatology, (MC 624)

808 S. Wood, RM 376 CME

Chicago, IL 60612

PH: (312) 996-0734

Fax: (312) 355-0870

Primary Physician - Dr. Carlotta Hill

email: chhill@uic.edu

Public Health Nurse – Gladys Lee, RN

email: FLLee@uic.edu**LOS ANGELES HD CLINIC**

LAC+USC Medical Center

1200 N. State St.

Clinic Tower A5B123

Los Angeles, CA 90033

PH: (323) 409-5240

Fax: (323) 441-8152

Primary Physician - Dr. Maria T. Ochoa

email: mariatoc@usc.edu

PH: (323) 226-3373

Public Health Nurse - Helen Mora, RN

email: hmora@dhs.lacounty.gov

Occupational Therapist - Rob Jerskey

email: robjerskey@yahoo.com**MARTINEZ HD CLINIC**

Contra Costa Regional Medical Center

Outpatient Specialty Clinic

2500 Alhambra Avenue

Martinez, CA 94553

PH: (925) 370-5868

Fax: (925) 370-5529

Primary Physician - Drs. Sutherland/Saffier

email: ssutherland@hsd.co.contra-costa.ca.us

PH: (925) 370-5867

email: ksaffier@yahoo.com

PH: (925) 370-5200 Ext.:4743

Public Health Nurse – Barbara Hobson, RN

PH: (925) 313-6757

email: Barbara.Hobson@hsd.cccounty.us

Community Health Worker – Sebastian Basalic

email: Sebastian.Basalic@hsd.cccounty.us**MIAMI HD CLINIC**

Jackson Memorial Hospital

1611 N.W. 12th AvenueACC East – 2nd Floor

Department of Dermatology

Miami, FL 33136-1096

PH: (305) 585-7348

Fax: (305) 585-6397

Primary Physician - Dr. Anne Burdick

email: Aburdick@med.miami.edu

Public Health Nurse - Gail Chepenik, RN

email: gchepenik@jhsmiami.org**NEW YORK HD CLINIC**

Bellevue Hospital Center

Department of Dermatology

462 First Avenue, Room 17-N-7

New York, NY 10016

PH: (212) 562-5670

Fax: (212) 263-6423

Primary Physician - Dr. William Levis

email: william_levis@yahoo.com

Public Health Nurse - Lydia Macwan, RN

PH: (212) 562-6096

email: Lydia.Macwan@bellevue.nychhc.org

Physical Therapist - Louis Iannuzzi, P.T., C.Ped.

email: Lni1@nyu.edu**PHOENIX HD CLINIC**

Maricopa County Health Department

1645 East Roosevelt Street

Phoenix, Arizona 85006

PH: (602) 372-2039

Fax: (602) 372-3862

Primary Physician - Dr. Ronald Pust

Tucson Office: (520) 626-5650

Cell: (520) 668-6441

email: rpust@email.arizona.edu

Public Health Nurse - Eileen Smith, RN

PH: (602) 372-2039

email: eileensmith@mail.maricopa.gov

Physical Therapist - Tracy Carroll, MPH

email: tc Carroll@email.arizona.edu

SAN DIEGO HD CLINIC

HHSA, North Central Regional Center
5055 Ruffin Road, Mail Stop: N-513
San Diego, CA 92123
PH: (858) 573-7338
Fax: (858) 573-7325

Primary Physician - Dr. Erik O. Gilbertson

email: erik.gilbertson@sdcounty.ca.gov

Public Health Nurse – Gina Sandoval, RN, PHN

email: regina.sandoval@sdcounty.ca.gov

SAN JUAN HD CLINIC

University of Puerto Rico
Medical Sciences Campus
School of Medicine - Dept. of Dermatology
P. O. Box 365067

San Juan, PR 00936-5067

PH: (787) 765-7950

Fax: (787) 767-0467

Primary Physician - Dr. Pablo Almodo'var

email: dermatol.rcm@upr.edu

Public Health Nurse - Sonia Santos-Expo'sito, RN, BSN

PH: (787) 758-2525, Ext. 5503

email: sonia.santos@upr.edu

SEATTLE HD CLINIC

Harborview Medical Center
2 West Clinic – 359930, 325 Ninth Avenue
Seattle, WA 98104

PH: (206) 520-5000

Toll Free #: 1-877-520-5000

Fax: (206) 744-5109

Primary Physician - Dr. James Harnisch

email: jpharnisch@comcast.net

Public Health Nurse – Angela Bartels, RN

email: bartelsa@uw.edu

SPRINGDALE HD CLINIC

Joseph H. Bates Outreach Clinic of Washington County

614 E. Emma Avenue, Suite 247

Springdale, AR 72764

PH: (479)-751-3630

Fax: (479)-751-4838

Primary Physician: Linda McGhee, MD

PH: (479) 521-0263

PH: (479) 973-8450 (office)

email: lmcghee@uams.edu

Public Health Nurse - Sandy Hainline Williams, RN

PH: (479) 751-3630

Cell: (479) 422-0190

email: sandra.hainline@arkansas.gov

TEXAS HD CLINICS

Department of State Health Services

Hansen's Disease Program

P. O. Box 149347, Mail Code 1939

Austin, TX 78714-9347

PH: (800) 252-8239

Fax: (512) 365-7824-primary fax

Fax: (512) 533-3167-secondary fax

Nurse Consultant: Linda Brown, MS, RN

PH: (512) 533-3144

email: lindaj.brown@dshs.state.tx.us

Officer Administrator: Kirbi Woods

PH: (512) 739-1876

email: kirbi.woods@dshs.state.tx.us

Dallas County Health & Human Services

2377 N. Stemmons Freeway, Suite 522

Dallas, TX 75207-2710

PH: (214) 819-2010

Fax: (214) 819-6095

Physicians - Dr. Jack Cohen/Dr. Sharon Nations

email: jbcohendo@aol.com

PH: (817) 753-6633 (private practice)

email: sharon.nations@utsouthwestern.edu

PH: (214) 645-8800

Public Health Nurse - Nancy Bernstein, RN, BSN

email: nbernstein@dallascounty.org

Houston Hansen's Disease Clinic

Northside Health Center

8504 Schuller Street

Houston, TX 77093

PH: (832) 393-4804

Fax: (832) 393-5247

Physician - Dr. Terry Williams/Dr. Steven Mays

email: Tmwill3502@aol.com

PH: (281) 332-8571

email: Steven.Mays@uth.tmc.edu

PH: (713) 500-8329

Public Health Nurse – Marion Matsu, RN, CCM

email: Marion.Matsu@houston.tx.gov

Main: (832) 393-4798

Cell: (832) 248-7150

Texas Center for Infectious Disease

2303 S. E. Military Drive

San Antonio, TX 78223

PH: (210) 531-4526

Fax: (210) 531-4508

Physician - Dr. Adriana Vasquez

PH: (210) 531-4565

email: adriana.vasquez@dshs.state.tx.us

Physician - Dr. Lynn Horvath

PH: (210) 531-4524

email: lynn.horvath@dshs.state.tx.us

Public Health Nurse - Debbie Mata, RN

PH: (210) 531-4576

PH: (210) 531-4295

Cell: (210) 389-3568

Appointment Secretary: (210) 531-4526

email: debbie.mata@dshs.state.tx.us

Department of State Hlth Services Region (HSR) 11

601 W. Sesame Drive

Harlingen, TX 78550

PH: (956) 423-0130

Fax: (956) 444-3295

Physician - Dr. Richard Wing

email: richard.wing@dshs.state.tx.us

Public Health Nurse – Grace Flores, RN

PH: (956) 423-0130, Ext. 5573

email: grace.flores@dshs.state.tx.us

Other Clinics

HAWAII HD CLINIC

Hawaii State Department of Health
Hansen's Disease Community Program
3650 Maunalei Avenue
Honolulu, HI 96816
PH: (808) 733-9831
Fax: (808) 733-9836

Program Manager: Lori Ching, RN
Direct Line/Voice Mail: (808) 733-4663
email: lori.ching@doh.hawaii.gov

Office Physical Address:
Diamond Head Health Center
3627 Kilauea Avenue Room 102
Honolulu, HI 96816