TEXAS
Health and Human Services

Texas Department of State Health Services

Hansen's Disease: History, Clinical Overview, and Nursing Care in the Texas Public Health System

Texas Department of State Health Services

Tuberculosis and Hansen's Disease Unit

January 24, 2024

Hansen's Disease (HD) Fact or Fiction

True or False:

HD is caused by someone's beliefs, sins, or a curse.

False. Upon discovery of the bacteria that causes HD, the healthcare community realized it was an infection and not a curse.

HD providers continue to educate the public today in an attempt to dispel this myth and reduce stigma associated with the illness.

Hansen's Disease (HD) Fact or Fiction

True or False:

Having HD can make your fingers or toes fall off.

False. HD is a disease of the nerves; untreated, or diagnosed late, nerve damage may cause loss of sensation and as a result, wounds (i.e., burns) can cause tissue damage.

Hansen's Disease (HD) Fact or Fiction

True or False:

HD is highly contagious and spreads easily from person to person.

False. While HD can be passed to another person, communicability is low. It would likely take prolonged exposure to the bacteria, a genetic predisposition to infection, and poor immune response for a contact to become infected.

Hansen's Disease (HD) Fact or Fiction

Fill in the blank:

___ % of the population is thought to have a natural immunity to Mycobacterium leprae.

95

Hansen's Disease (HD) Fact or Fiction

Select all that apply:

Known vector(s) of HD are:

a. The 5-banded armadillo

b. The 8-banded armadillo

c. The 9-banded armadillo

d. The U.K.'s red squirrel

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Hansen's Disease (HD) Fact or Fiction

True or False:

HD is treatable and people can be cured.

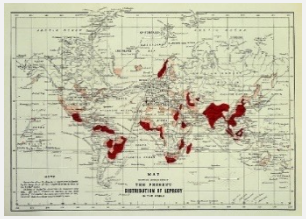
True. HD is treated and can be cured with proper multi-drug therapy (MDT). However, deformity and disability may be life-long, and patients may need treatment even after M. leprae bacteria are killed.

History of Hansen's Disease

Fact vs. Fiction

- Slow-growing bacterial disease of the skin and peripheral nerves
- Not highly contagious
- Can be cured with medications
- History of fear, stigmatization, and misconceptions

History of Hansen's Disease



Alexander the Great, Asia
325 B.C.E.

Atharva Veda, 2000 B.C.E;
skeletal remains, India

Possible earliest evidence

Medieval Times Quarantine

Segregation in Europe

- Bells or clappers used to signal presence of someone with HD
- Face and skin were covered
- Fear surrounded the disease and those suffering were isolated

Image credit: Late fifteenth century painting of a leper shaking a rattle or bell to announce his presence. 2023. Medievalists.net. https://www.medievalists.net/2015/01/make-middle-ages/medieval-leprosy-genome-explains-sudden-decline/

Middle Ages

Leper House.—Miniature from the "Miroir Historical" of Vincent d
Manuscript of the Thirteenth Century.

Image credit: Duncan 1890. Leper house. Stock photo. Getty images. https://www.gettyimages.com/detail/illustration/leper-house-royalty-free-illustration/466051467

- "Leprosy" became the term used to describe this illness
- Hospitals were known as "Leprosariums" or "Lazar homes"
- 1100-1400 C.E. rise and then sharp decline of the disease

History of Hansen's Disease

Alexander the Great, Asia
325 B.C. E.

1100-1400 C.E. rise then notable decline, Europe

Atharva Veda, 2000 B.C.E.; skeletal remains, India

Possible earliest evidence

Quarantine and law continues, Middle Ages
500-1500 C. E.

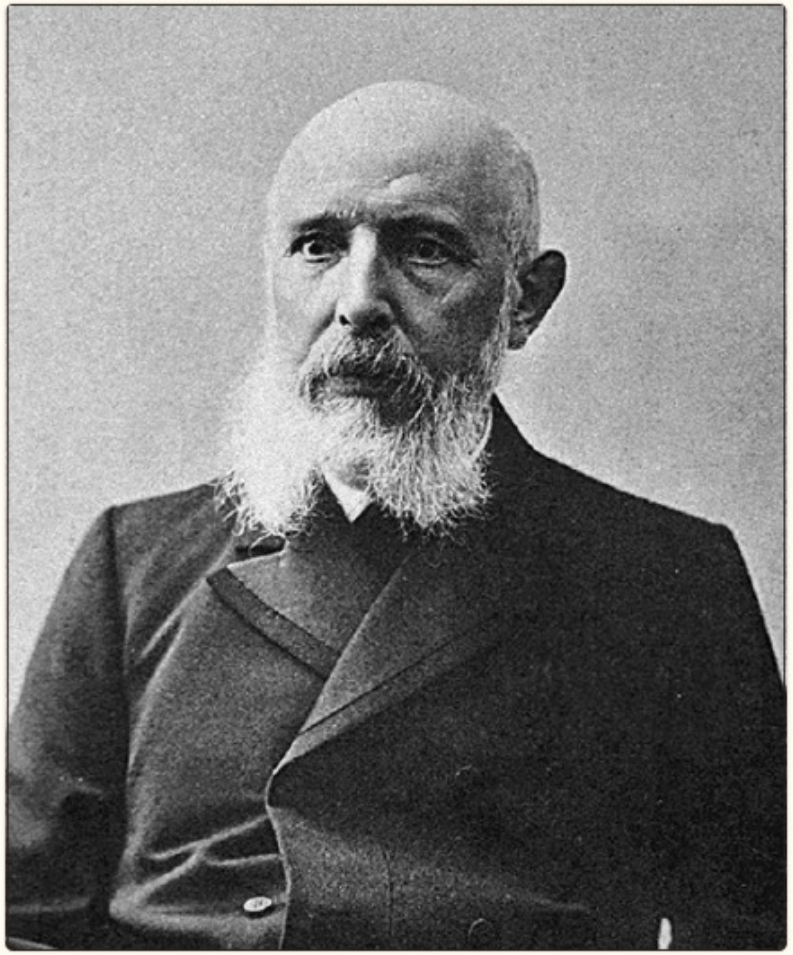
1873 Gerhard Henrik Armauer Hansen identifies the bacteria that causes "leprosy"

Golden Age of Discovery

Gerhard-Henrik Armauer Hansen

- Norwegian scientist and physician
- Believed microorganisms (germs) caused human disease
- 1873 identified the Lepra bacilli
- Previous belief was that leprosy was hereditary or caused by a curse
- Discovery led to quarantine and isolation to minimize the spread

https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4458930/



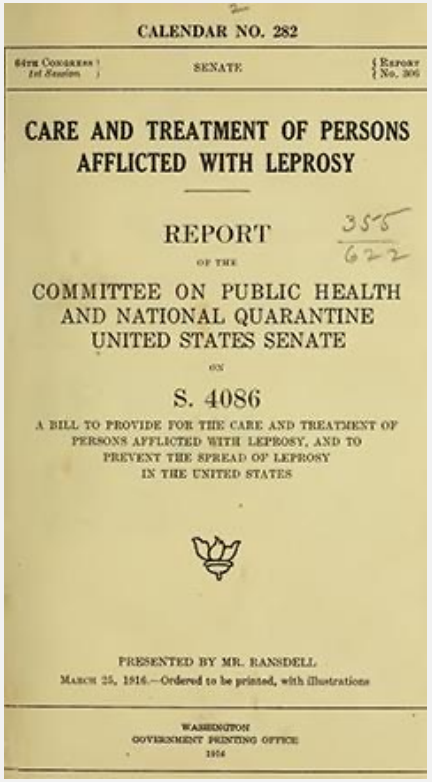
Worldwide Segregation

Photo credit: Batsutoland (Cape Colony). International Leprosy Association (2023). https://leprosyhistory.org/geographical_region/area/africa

Photo credit: 1 Peso Culion Island leper colony. Numista (2023). https://en.numista.com/catalogue/exonumia21631.html

Hansen's Disease in U.S.

- HD was reported in the U.S. including many cases in Louisiana by the 1750s
- 1890s, the public demanded "pest houses" be moved out of city limits
- 1896, nuns moved into a deserted plantation to establish the *Louisiana Leper Home*
- 1917, the plantation site, located in Carville, was officially established by Senate Bill 4086 as a National Leprosarium



CALENDAR NO. 282

64TH CONGRESS, 1st Session — SENATE — REPORT No. 306

CARE AND TREATMENT OF PERSONS AFFLICTED WITH LEPROSY

REPORT

OF THE

COMMITTEE ON PUBLIC HEALTH AND NATIONAL QUARANTINE UNITED STATES SENATE

ON

S. 4086

A BILL TO PROVIDE FOR THE CARE AND TREATMENT OF PERSONS AFFLICTED WITH LEPROSY, AND TO PREVENT THE SPREAD OF LEPROSY IN THE UNITED STATES

PRESENTED BY MR. RANSDELL

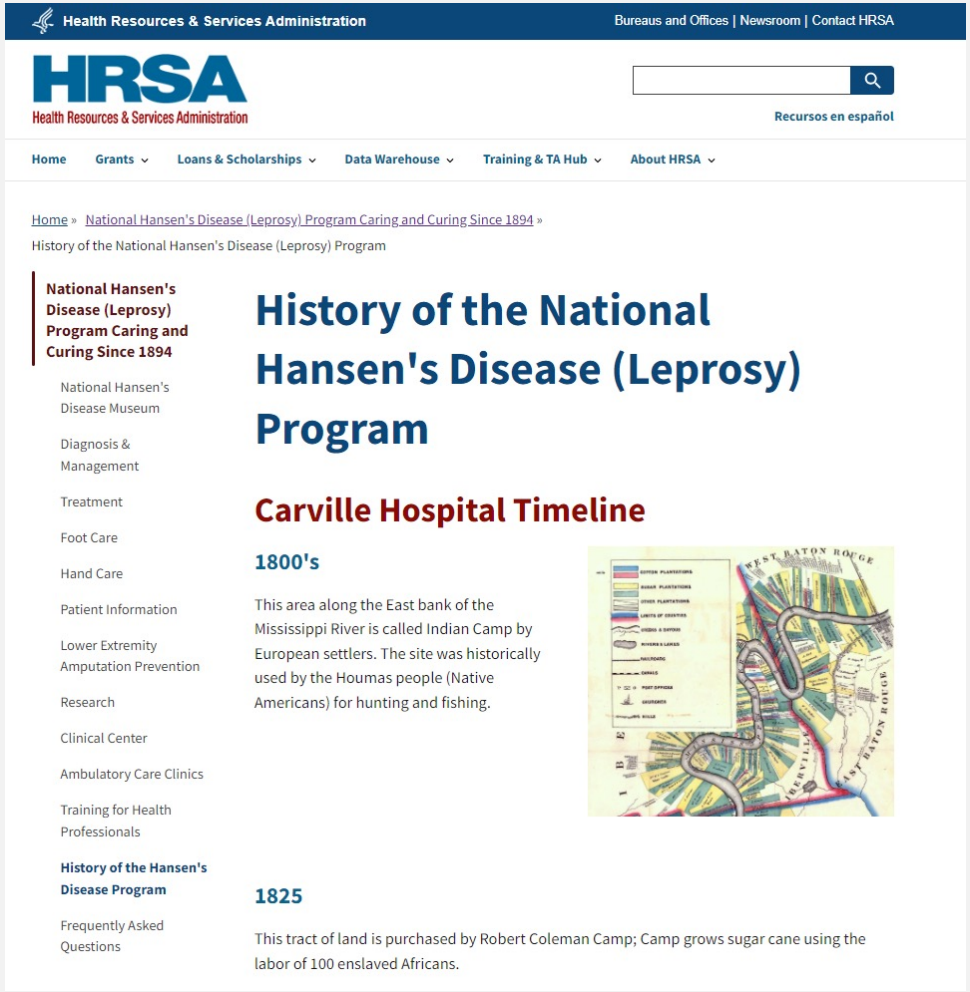
MARCH 25, 1916.—Ordered to be printed, with illustrations

WASHINGTON
GOVERNMENT PRINTING OFFICE
1916

Photo credit: Library of Congress. https://tile.loc.gov/storage-services/public/gdcmassbookdig/caretreatmentofp00unit/caretreatmentofp00unit.pdf

Carville's History

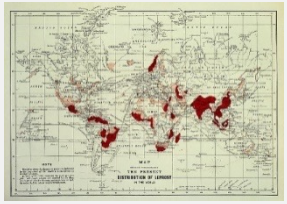
- Carville managed inpatients with HD
- Committed to research and treatment
- Pioneered drug therapy options
- Full history: https://www.hrsa.gov/hansens-disease/history



Transition to Outpatient Care

- 1921 Carville was sold to the U.S. government for care of those with HD
- 1931 patients advocated the name “leprosy” be changed to “Hansen’s disease”
- 1882-1970s mandatory hospitalization
- 1981 outpatient care established

History of Hansen's Disease



Alexander the Great, Asia
325 B.C. E.

1100-1400 C.E. rise then notable decline, Europe

1882-1970s mandatory hospitalization

1921 Federal government purchases "Carville"

1981, Multi-drug therapy

Atharva Veda, 2000 B.C.E; skeletal remains, India

Possible earliest evidence

Quarantine and law continues, Middle Ages 500-1500 C. E.

1931 STAR advocates name change to Hansen's Disease

1873 Gerhard Henrik Armauer Hansen identifies the bacteria that causes "leprosy"

U.S. Ambulatory Care Clinics (ACCs) established for outpatient care

Hansen's Disease Ambulatory Care Clinics (ACCs) Today

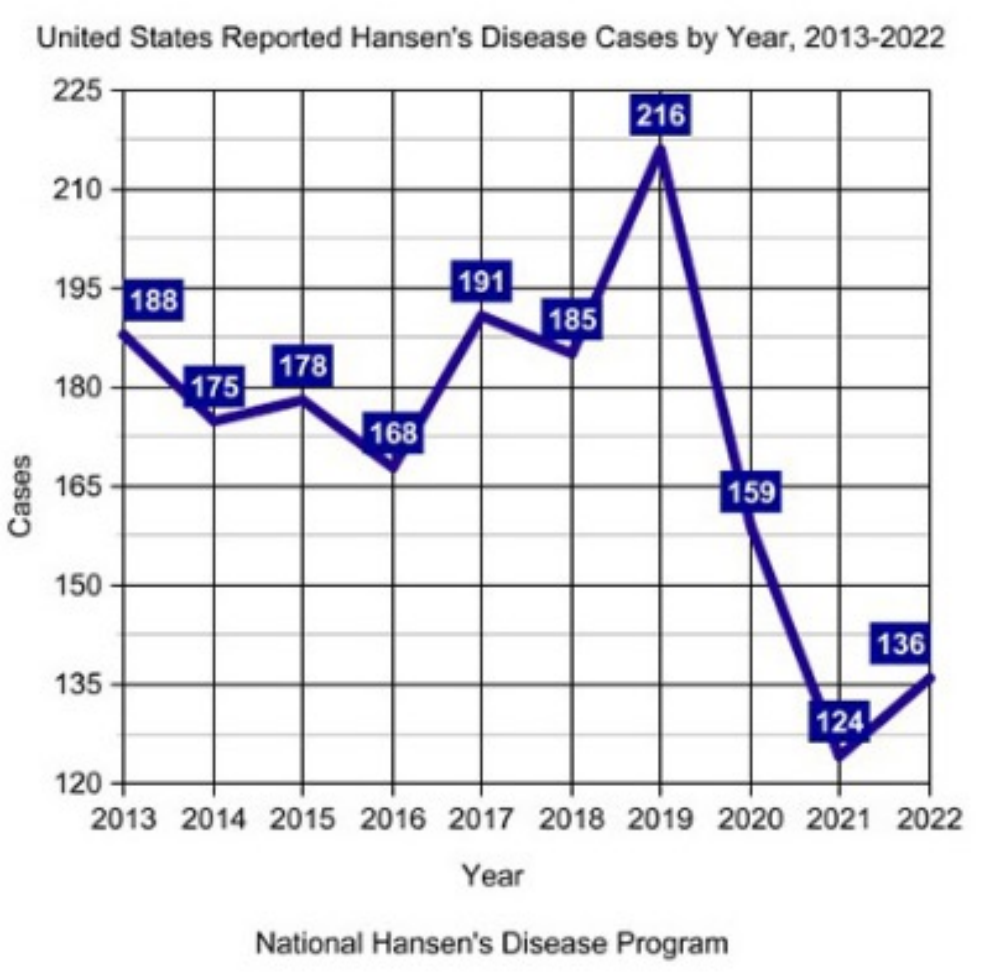
Federally funded through the National Hansen's Disease Program (NHDP), an activity operationalized through the Health Resources and Services Administration (HRSA).

1) State of Arkansas, AR
2) University of Puerto Rico, San Juan, PR
3) Harborview Medical Center, Seattle, WA
4) County of Los Angeles, CA
5) Lahey Clinic, Burlington, MA
6) Public Health Trust of Miami-Dade County, FL
7) New York City Health and Hospitals, NY
8) County of San Diego, CA
9) Texas Department of State Health Services, TX
10) Emory University, Atlanta, GA
11) Wesley Community Center, Phoenix, AZ
12) University of Illinois, IL

Epidemiology of HD

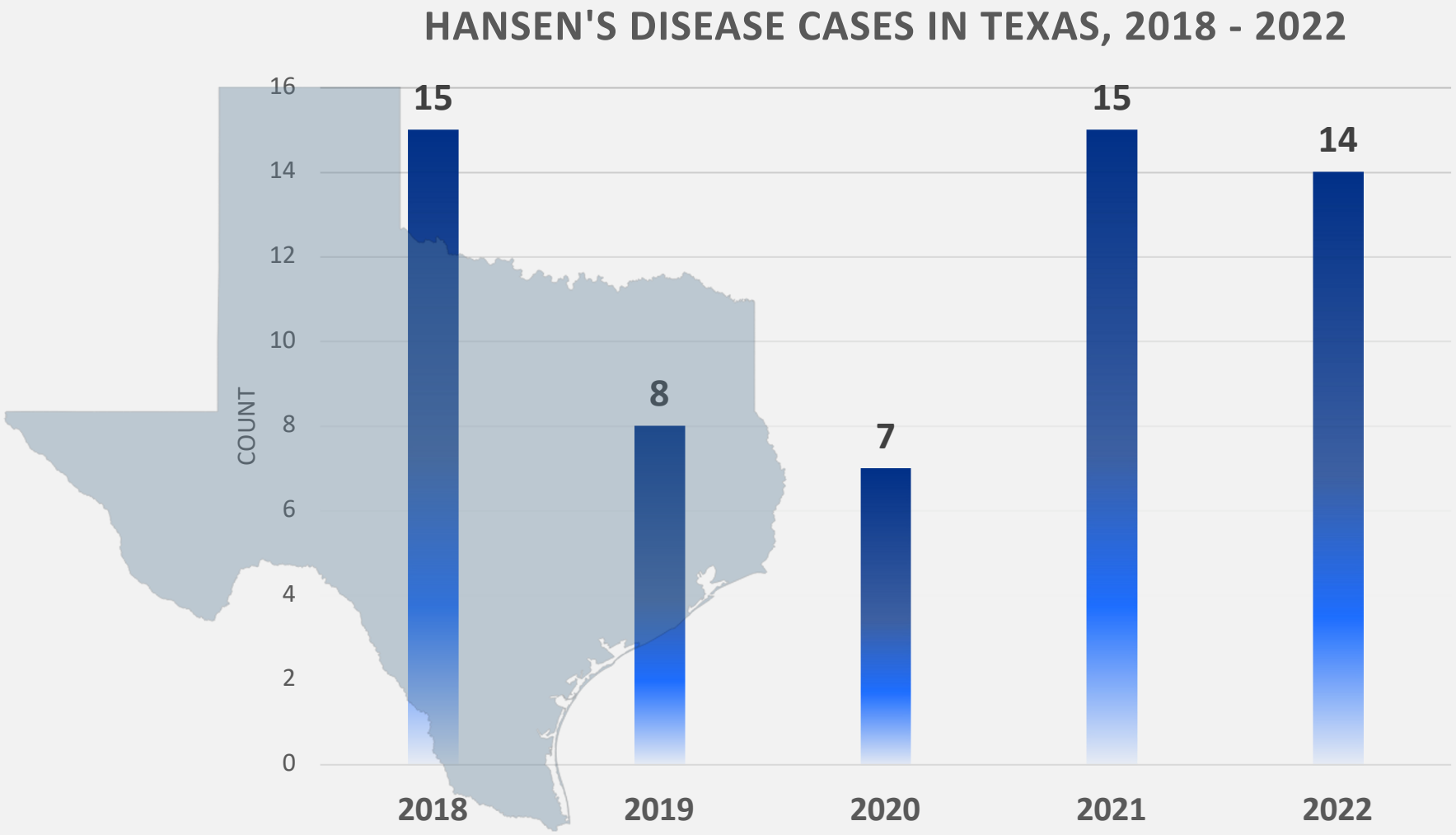
Hansen's Disease Epidemiology

- Worldwide, over 200,000 new cases are reported (WHO, 2023)
  - Reported from or 120 countries
- In the U.S., 136 new cases were reported in 2022 as per the National Hansen's Disease Program (NHDP)



Credit: National Hansen's Disease Program (2023). https://www.hrsa.gov/hansens-disease

Hansen's Disease Cases in Texas, 2018 - 2022



Source: DSHS Hansen's Disease Program

Risk, Transmission, and Treatment

Microbiology

- *M. leprae* is an acid-fast bacillus
- Multiplies very slowly (generation time 12.5 days)
- Grows best at 27° to 33°C
- *M. leprae has* never been cultured in artificial media
- Will multiply in animal species, such as mouse foot pad

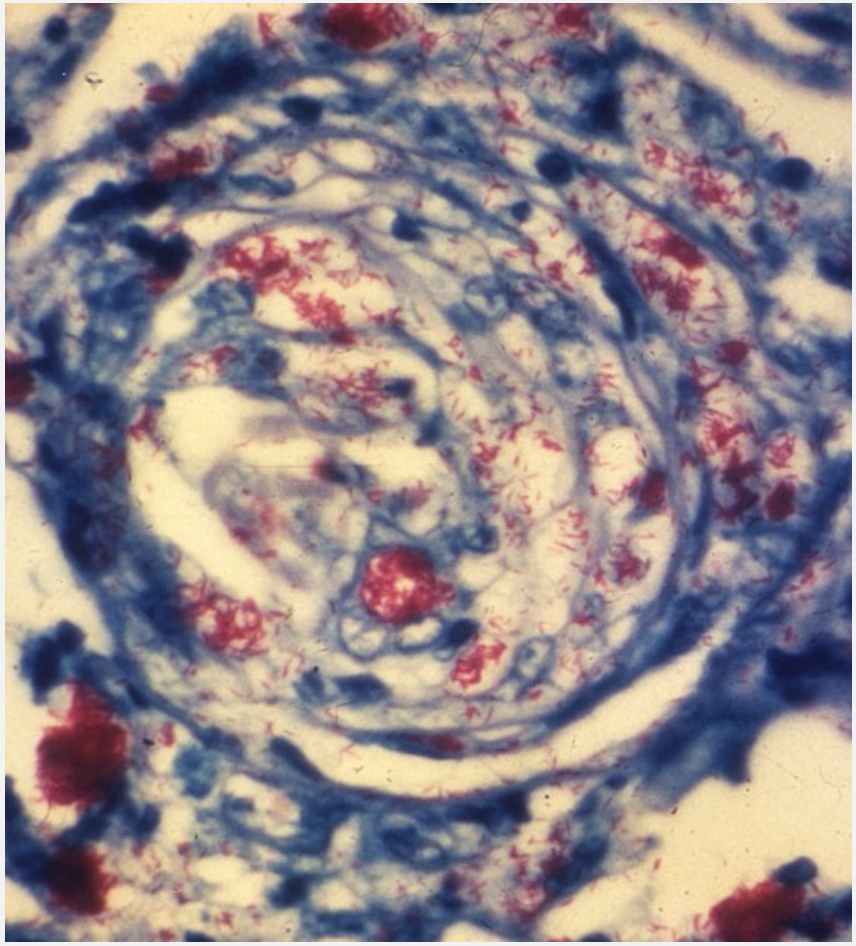


Photo credit: CDC/Arthur E. Kay. Public Health Image Library (2014, February 11). Skin tissue sample from a patient with leprosy. http://www.publicdomainfiles.com/show_file.php?id=13921668623335

Routes of Transmission

- The definitive route of transmission has not been proven
- Probably spread by the respiratory route similar to tuberculosis
- Nasal discharge from untreated multibacillary patients often contains large numbers of bacilli

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Vector: 9-Banded Armadillo

Hansen's Disease Risk

- 95 percent of human population has a natural immunity
- Risk factors may include living in a high incidence country and prolonged, close contact to someone with untreated HD
- Greatest risk is for family members of a person with *untreated* disease
  - Possible genetic susceptibility
  - Possible prolonged contact
  - Spouse is least likely; children, siblings, and parents have greatest risk

https://www.cdc.gov/leprosy/transmission/index.html

Ways HD is Not Spread

- Far less contagious than other infectious diseases.
- Not passed on from a mother to her unborn baby during pregnancy.
- Not transmitted through sexual contact.
- Not acquired from casual contact.
- Healthcare workers rarely contract Hansen's disease.

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Clinical Overview of the Disease

Signs and Symptoms

Initial symptoms can include:

- Numbness to peripheral sites; loss of temperature sensation

As disease progresses:

- Increase in loss of sensation (touch, pain, deep pressure)

Long term sequalae:

- Ulcers, skin lesions, hypopigmented macules, eye damage, loss of digits, facial disfigurement (collapsed septum, loss of eyebrows)

Other:

- Early signs are subtle
- Patients report multiple healthcare provider encounters before it is diagnosed
- Can report onset of symptoms 10 years prior to diagnosis

Spectrum of Leprosy

Paucibacillary Disease

Patient may have 1-5 lesions

"Tuberculoid"

Types include:

- Indeterminate (I)
- Tuberculoid (TT)
- Borderline tuberculoid (BT)

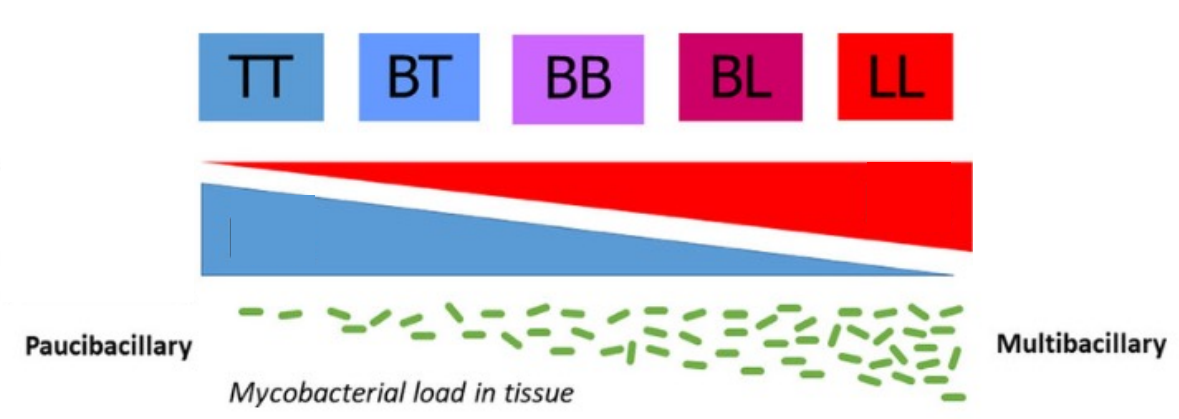
Multibacillary Disease

Patient will have ≥ 6 lesions

"Lepromatous"

Types include:

- Mid-Borderline (BB)
- Borderline Lepromatous (BL)
- Lepromatous (LL)



Paucibacillary Disease

Photo Credit: Centers for Disease Control and Prevention (CDC, 2017). Paucibacillary leprosy. https://www.cdc.gov/leprosy/health-care-workers/clinical-diseases.html

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Multibacillary Disease

Photo credit: Franco-Paredes C, Garcia-Creighton E, Henao-Martínez A, et al. Novel approaches in the treatment of Hansen's disease (Leprosy): a case series of multidrug therapy of monthly rifampin, moxifloxacin, and minocycline (RMM) in the United States. *Therapeutic Advances in Infectious Disease*. 2022;9. doi:10.1177/20499361221135885

Diagnosis

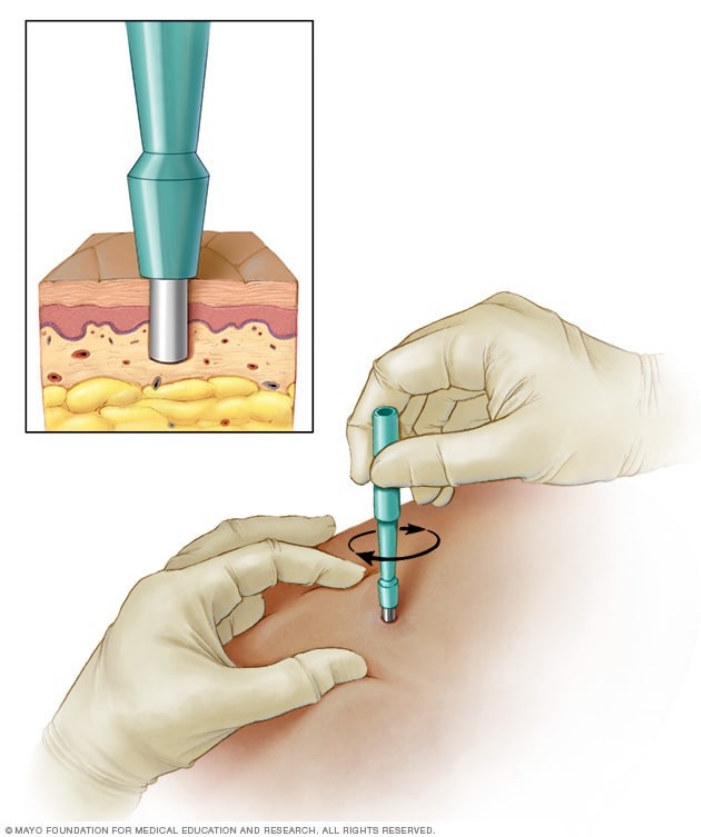
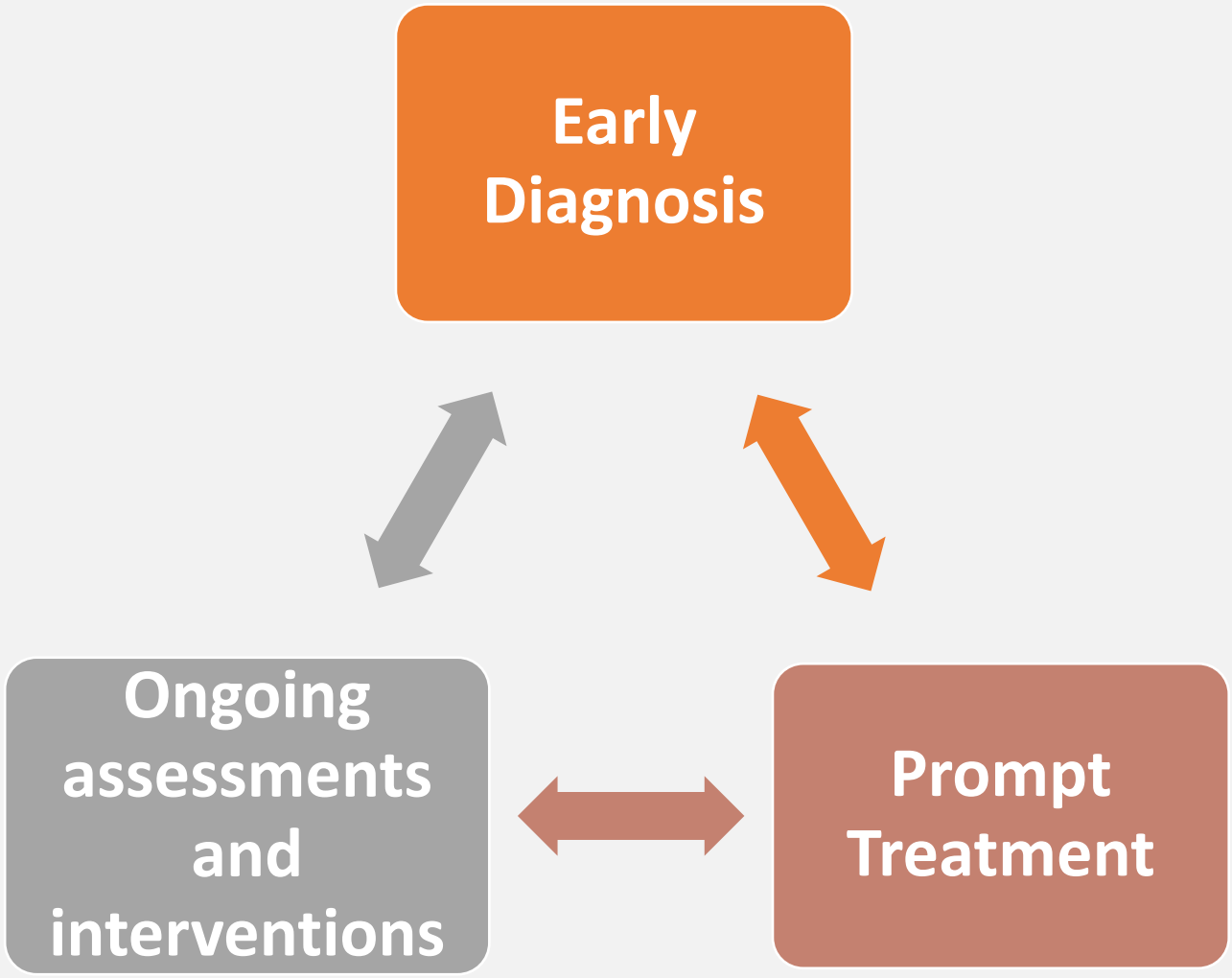


Image credit: Mayo Clinic. (2023). Punch biopsy. https://www.mayoclinic.org/tests-procedures/skin-biopsy/multimedia/punch-biopsy/img-20005764

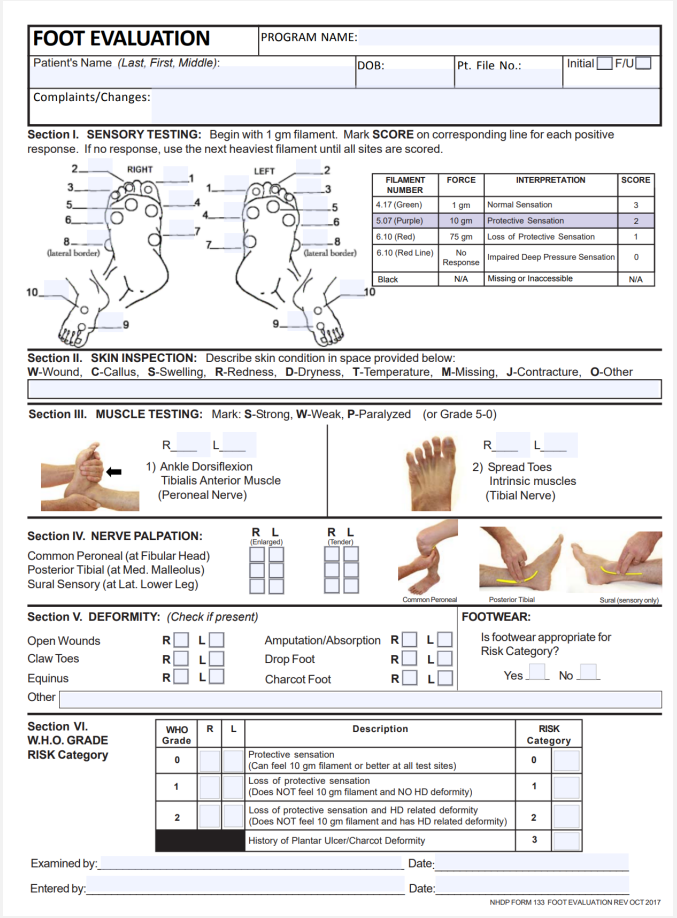
- In U.S., diagnosis is made with a punch biopsy
- A fite stain is performed to identify acid-fast bacilli (AFB)
- A polymerase chain reaction (PCR) test at the NHDP laboratory can identify the genome:
  - M. leprae
  - M. lepromatosis

Preventing Deformity and Disability



Baseline Assessments

- Visual inspection of the skin, body
- Hand, foot screens to assess and track sensation, strength, any deformities
- Baseline labs now include interferon gamma release assay (IGRA)
- No blood test in U.S. to diagnose HD



FOOT EVALUATION PROGRAM NAME:

Patient's Name *(Last, First, Middle)*: DOB: Pt. File No.: Initial ☐ F/U ☐

Complaints/Changes:

Section I. SENSORY TESTING: Begin with 1 gm filament. Mark **SCORE** on corresponding line for each positive response. If no response, use the next heaviest filament until all sites are scored.

RIGHT LEFT (lateral border)

FILAMENT NUMBER	FORCE	INTERPRETATION	SCORE
4.17 (Green)	1 gm	Normal Sensation	3
5.07 (Purple)	10 gm	Protective Sensation	2
6.10 (Red)	75 gm	Loss of Protective Sensation	1
6.10 (Red Line)	No Response	Impaired Deep Pressure Sensation	0
Black	N/A	Missing or Inaccessible	N/A

Section II. SKIN INSPECTION: Describe skin condition in space provided below:
W-Wound, **C**-Callus, **S**-Swelling, **R**-Redness, **D**-Dryness, **T**-Temperature, **M**-Missing, **J**-Contracture, **O**-Other

Section III. MUSCLE TESTING: Mark: **S**-Strong, **W**-Weak, **P**-Paralyzed (or Grade 5-0)

R___ L___ 1) Ankle Dorsiflexion Tibialis Anterior Muscle (Peroneal Nerve)

R___ L___ 2) Spread Toes Intrinsic muscles (Tibial Nerve)

Section IV. NERVE PALPATION:
Common Peroneal (at Fibular Head)
Posterior Tibial (at Med. Malleolus)
Sural Sensory (at Lat. Lower Leg)

R L (Enlarged) R L (Tender)

Common Peroneal Posterior Tibial Sural (sensory only)

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

Open Wounds R ☐ L ☐ Amputation/Absorption R ☐ L ☐
Claw Toes R ☐ L ☐ Drop Foot R ☐ L ☐
Equinus R ☐ L ☐ Charcot Foot R ☐ L ☐
Other

FOOTWEAR: Is footwear appropriate for Risk Category? Yes ___ No ___

Section VI. W.H.O. GRADE RISK Category

WHO Grade	R	L	Description	RISK Category	
0			Protective sensation (Can feel 10 gm filament or better at all test sites)	0	
1			Loss of protective sensation (Does NOT feel 10 gm filament and NO HD deformity)	1	
2			Loss of protective sensation and HD related deformity (Does NOT feel 10 gm filament and has HD related deformity)	2	
			History of Plantar Ulcer/Charcot Deformity	3	

Examined by:_____ Date:_____
Entered by:_____ Date:_____

NHDP FORM 133 FOOT EVALUATION REV OCT 2017

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Treatment for HD

Multi-drug therapy with the following, varying combinations:

- Rifampin
- Dapsone
- Clofazimine
- Moxifloxacin
- Clarithromycin
- Minocycline

Multi-Drug Therapy Regimen

ADULTS		
Tuberculoid (TT & BT) WHO Classification Paucibacillary (PB)		
Agent	Dose	Duration
Option 1		
Dapsone	100 mg daily	12 months, then discontinue
Rifampin	600 mg daily	
Option 2		
Dapsone	100 mg daily	12 months, then discontinue
Rifampin	600 once a month**	
Lepromatous (LL, BL, BB) WHO Classification Multibacillary (MB)		
Agent	Dose	Duration
Option 1		
Dapsone	100 mg daily	24 months, then discontinue
Rifampin	600 mg daily	
Clofazimine	50 mg daily	
Option 2		
Dapsone	100 mg daily	24 months, then discontinue
Rifampin	600 once a month**	
Clofazimine	50 mg daily	

https://www.hrsa.gov/hansensdisease/diagnosis/recommendations

Novel HD Regimen

Once Monthly Rifampin/Moxifloxacin/Minocycline (RMM)

ADULTS		
Tuberculoid (TT & BT) WHO Classification Paucibacillary (PB)		
Agent	Dose	Duration
Rifampin	600mg once a month	12 months, then discontinue
Moxifloxacin	400mg once a month	
Minocycline	100mg once a month	
Lepromatous (LL, BL, BB) WHO Classification Multibacillary (MB)		
Agent	Dose	Duration
Rifampin	600mg once a month	24 months, then discontinue
Moxifloxacin	400mg once a month	
Minocycline	100mg once a month	

https://www.hrsa.gov/hansensdisease/diagnosis/recommendations

Clofazimine Use

- Clofazimine is only available in the U.S. as an investigational new drug (IND) under the Food and Drug Administration (FDA).

- Used in multi-drug therapy regimens.
- Can cause hyperpigmentation leading to stigmatization and/or embarrassment of patients.
- Providers must assess patient's response to CFZ and can consider other treatment options.

Photo credit: Franco-Paredes C, Garcia-Creighton E, Henao-Martínez A, et al. Novel approaches in the treatment of Hansen's disease (Leprosy): a case series of multidrug therapy of monthly rifampin, moxifloxacin, and minocycline (RMM) in the United States. *Therapeutic Advances in Infectious Disease*. 2022;9. doi:10.1177/20499361221135885

Managing Reactions

- HD reactions occur when the immune system responds to the bacteria (and can “flair” when the bacteria start to die)
- Three types:
  - Reversal reaction
  - Erythema nodosum leprosum (ENL) reaction
  - Lucio’s phenomenon (rare)
- Reactions can lead to a patient needing long-term care in the HD clinic, even when HD is cured
- Goal of pharmacological therapy: **Reduce the immune response and reduce inflammation**

Thalidomide (Thalomid)

- Used to treat HD reactions.
- **Black-box warning**: can cause embryo-fetal toxicity, severe birth defects, and venous thromboembolism.
- Extensive patient education is required.
  - Bristol Myers Squibb (BMS) provides thalomid via Celgene.
- Close monitoring and pregnancy prevention required; patient must take monthly surveys.

The Guardian

My thalidomide family: Every time I went home I was a stranger

Louise Medus was one of the last babies born with the effects of the drug thalidomide. Brought up in a residential home from infancy, She's had to fight to overcome her tough start in life and build a family life of her own

Louise Medus-Mansell and Darren Mansell at home in Cheltenham. Photograph: Adrian Sherratt for the Guardian Photograph: Adrian Sherratt/Guardian

'I can't imagine what my dad thought or felt when a grim-faced doctor led him to a delivery room an hour after my birth," says Louise Medus. "All I

https://www.theguardian.com/lifeandstyle/2014/aug/01/thalidomide-louise-medus-a-stranger-when-i-went-home

Treatment to Cure

Photo credit: Franco-Paredes C, Garcia-Creighton E, Henao-Martínez A, et al. Novel approaches in the treatment of Hansen's disease (Leprosy): a case series of multidrug therapy of monthly rifampin, moxifloxacin, and minocycline (RMM) in the United States. *Therapeutic Advances in Infectious Disease*. 2022;9. doi:10.1177/20499361221135885

Texas HD Clinic Structure

Hansen's Disease Clinic Structure in Texas

- Managed by public health departments
- Each clinic has an experienced HD physician
- Each clinic has an experienced HD registered nurse
- Ancillary care providers as necessary:
  - ophthalmology
  - orthotics (specialty shoes)
  - behavioral health

Role of the Nurse Case Manager

- Patient education- stigma, treatment, plan of care
- Family education on the disease and care
- Ongoing assessment of the hands, feet due to neuropathy
- Referrals to ancillary care
- Medication administration and education
- Monitoring for HD reactions

Goal: prevent deformity and disability and cure with positive patient outcomes

Clinical Consultation

- **Consultation available with the National Hansen's Disease Program (NHDP):**
- Phone 1-800-642-2477, weekdays 9 a.m. to 5:30 p.m. EST
- Hawaii: 1-808-733-9831.

https://www.hrsa.gov/hansens-disease/diagnosis

World Leprosy Day

Raising Awareness

- World Health Organization recognizes World Leprosy Day the last Sunday in January each year
  - Aim: *"create awareness against the stigma attached to the disease, by making the general community aware that it is a disease spread by a type of bacteria and it can be easily cured"*
- 2024 theme: ***Ending Stigma, Embracing Dignity***
- Resources to post and provide education:
  - https://www.who.int/campaigns/world-leprosy-day

Acknowledgments

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National Hansen's Disease Program (NHDP)
https://www.hrsa.gov/hansens-disease

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Case Study