Hansen’s Disease Training and Surveillance Measures — U.S.-Affiliated Pacific Islands, 2012-2013

T. J. Doker, DVM, MPH
D. M. Scollard
M. G. Cabanos
H. Cross
D. D. Blaney
U.S.-Affiliated Pacific Islands (USAPIs)

1. Commonwealth of the Northern Marianas Islands
2. Republic of the Marshall Islands
3. Guam
4. Republic of Palau
5. Federated States of Micronesia
6. American Samoa
2010: National Leprosy Meeting (Majuro)

- Identified challenges
  - Surveillance: Data discrepancies; poor patient tracking
  - Training: Leprosy diagnosis and treatment
2010: Hansen’s Disease (HD) Patients from USAPIs as Percent of Total U.S. Patients

Data courtesy of National Hansen’s Disease Program
### 2002-2011: HD Patients by Country of Origin as Percent of Total Guam Patients, N=77

<table>
<thead>
<tr>
<th>Country</th>
<th># New Cases</th>
<th>n/N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Micronesia</td>
<td>67</td>
<td>87</td>
</tr>
<tr>
<td>Palau</td>
<td>4</td>
<td>5.2</td>
</tr>
<tr>
<td>Marshall Islands</td>
<td>1</td>
<td>1.3</td>
</tr>
<tr>
<td>Guam (U.S.)</td>
<td>1</td>
<td>1.3</td>
</tr>
</tbody>
</table>

Data courtesy of Cecilia Arciaga, Bureau of Communicable Disease Control, Guam
2012: Leprosy Elimination Workshop (Pohnpei)

- Marshall Islands, Micronesia, Kiribati
- Partners: WHO, CDC, NHDP, and ALM
- Key issues: Funding, surveillance
Web-based Surveillance System: EpiAnywhere

- Standardized patient form
- Data entry
- HD program managers
- Consultants
2013: Leprosy Training Workshops

- Peripheral Health Worker/EpiAnywhere training
- “Hands-on” workshops
  - History taking
  - Lesion exams
  - Nerve palpations
  - Sensory/motor testing
- Pre- and post-tests: ↑55%
Micronesia

Year

2008 2009 2010 2011 2012

Number New HD Cases

0 50 100 150 200 250 300

Hidden challenges
## New Cases and Prevalence, 2012

<table>
<thead>
<tr>
<th>Country</th>
<th>Population (X 1000)</th>
<th>New cases (Rate/10,000)</th>
<th>Prevalence (Rate /10,000)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Western Pacific Region</td>
<td>1,800,000</td>
<td>5,400 (0.03)</td>
<td>7,425 (0.04)</td>
</tr>
<tr>
<td>Marshall Islands</td>
<td>53</td>
<td>137 (25.8)</td>
<td>140 (26.4)</td>
</tr>
<tr>
<td>Micronesia</td>
<td>103</td>
<td>252 (24.5)</td>
<td>224 (21.7)</td>
</tr>
<tr>
<td>State of Chuuk, Micronesia</td>
<td>55</td>
<td>167 (30.4)</td>
<td>Data not available</td>
</tr>
<tr>
<td>Kiribati</td>
<td>101</td>
<td>94 (9.3)</td>
<td>77 (7.6)</td>
</tr>
</tbody>
</table>

*Data from WHO Weekly epidemiology record, No. 35, 30 August 2013, 88; 365-380*
## New Cases and Prevalence, 2012

<table>
<thead>
<tr>
<th>Country</th>
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<th>Prevalence (Rate /10,000)</th>
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</tbody>
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*Data from WHO Weekly epidemiology record, No. 35, 30 August 2013, 88; 365-380*
WHO Operational Guidelines

- **Case Detection**
  - Voluntary self-reporting promoted
  - Increase awareness/decrease stigma
  - Active not generally recommended

- **Household Contact Examinations**
  - Initial examinations upon new case detection
  - Education for self-referral
Exceptional Circumstances?

- 29 atolls/1200 islands
- 750,000 square miles
Exceptional Circumstances?

- **Within Lagoon**
  - 11 major islands
  - 46 smaller islands
- 41 reef islands
- 822 square miles
Way Ahead for Marshall Islands and Chuuk

- One-time small-scale campaigns
- Family contact screening
- National campaigns
Acknowledgements

- **Republic of Palau**
  - Connie Bieb Olikung

- **Guam**
  - Dr. Annakutty Mathew, Cecilia Teresa Arciaga

- **FSM**
  - Dr. Mayleen Jack Ekiek
  - Yap State, FSM
    - Dr. Vincent Tapleimal, Ivan Taueg
  - Chuuk State, FSM
    - Drs Lyma Setik and Dorina Fred, Loretta Lino
  - Pohnpei State, FSM
    - Dr. Elizabeth Keller, Rupihner Defang
  - Kosrae State, FSM
    - Dr. Carolee Masao, Foster Waguk

- **RNMI**
  - Dr. Daniel Lamar, Marci Rabauliman

- **American Samoa**
  - Dr. Saipale Fuimaono

- **RMI**
  - Dr. Tom Jack, Caroline Johnny
  - Majuro, RMI
  - Ebeye, RMI
  - 177 Project, RMI
  - Outer Islands, RMI

- **Hawaii HD Branch**
  - Michael Maruyama, Lori Anne Ching

- **NHDP**
  - Dr. Barbara Stryjewska

- **BSPB/CDC**
  - Drs. Willie Bower and Henry Walke

- **WPRO/WHO**
  - Drs. Catharina van Weezenbeek and Katsunori Osuga
Thank You
Questions?

For more information please contact Centers for Disease Control and Prevention

1600 Clifton Road NE, Atlanta, GA  30333
Telephone: 1-800-CDC-INFO (232-4636)/TTY: 1-888-232-6348
E-mail: cdcinfo@cdc.gov      Web:  http://www.cdc.gov

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.
2001-2010: RMI and FSM HD Patients in the United States*

Marshallese case (Total 105)
Micronesian case (Total 104)

*Data courtesy of NHDP
2010: Republic of Marshall Islands

Project 177 Atolls
### Patient Record Card, Page 1

- **Demographics**
- **Mode of Detection**
- **Signs of Leprosy**
- **Classification**
- **Type of Case**
- **Comorbidities**
- **Household Contact**

#### Examination

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### National Leprosy Elimination Program
Public Health Department, Ministry of Health

**Name of User Nation**

Leprosy Case Number: ______ (YYYY-####) Patient Record Number: ______ Date of Report (Diagnosis): ______

**PATIENT RECORD CARD**

#### Demographics

Name: ___________ Age: _____ Date of Birth: ______ (MM/DD/YYYY) Sex: Male ☐ Female ☐
Marital Status: ___________ Phone Number: ___________ Place/Atoll/Island of Birth: ___________
Current Address/Atoll/Island: ___________ If Migrant, When Arrived: ______ (MM/YYYY)

#### Mode of Detection

Voluntary ☐ Referral ☐ Household Contact ☐ Mass Screening ☐ School Survey ☐ Other: ___________

#### Signs of Leprosy at Diagnosis

- Patches: Yes ☐ No ☐ 
- Nodules: Yes ☐ No ☐ 
- Infiltrations: Yes ☐ No ☐ 

Total # Lesions: ______ Loss of Sensation: Yes ☐ No ☐ 
# of Lesions Affected: ______

Duration of Symptoms (in Months): ______ Reaction at Presentation: Yes ☐ No ☐ (If Yes, See Page 3)

<table>
<thead>
<tr>
<th>Slit Skin Smear</th>
<th>2nd (Date) Location on Body</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>1st (Date)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Biopsy</th>
<th>2nd (Date) Location on Body</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>1st</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

#### Classification

<table>
<thead>
<tr>
<th>Adult:</th>
<th>MB</th>
<th>Date MDT Started: ______ (MM/DD/YYYY)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child:</td>
<td>MB</td>
<td>Estimated Completion Date: ______ (MM/DD/YYYY)</td>
</tr>
</tbody>
</table>

#### Type of Case (Patient Status)

- New ☐ Return after Default ☐ Transfer-In ☐ Relapse ☐

#### Comorbidities

- Diabetes mellitus ☐ Tuberculosis ☐ HIV ☐ Hepatitis ☐ Other: ___________

#### Household Contact Examination

<table>
<thead>
<tr>
<th>Name</th>
<th>Age</th>
<th>Relationship</th>
<th>1st Exam (MM/DD/YYYY)</th>
<th>2nd Exam (MM/DD/YYYY)</th>
<th>Results/Remarks</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>Y1</td>
<td>Y2</td>
<td></td>
</tr>
<tr>
<td></td>
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<td>Y3</td>
<td>Y4</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Y5</td>
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</tr>
</tbody>
</table>
Patient Record Card, Page 2

- Body Chart
- Nerve Function Assessment
  - Nerve Examination
  - Sensation Testing
  - Muscle Strength Testing
- WHO Disability Grading
- Eye, Hand, and Foot Grading

### Nerve Function Assessment

#### Nerve Examination

<table>
<thead>
<tr>
<th>Upon Dx</th>
<th>Nerve</th>
<th>After TC</th>
</tr>
</thead>
<tbody>
<tr>
<td>R</td>
<td></td>
<td></td>
</tr>
<tr>
<td>L</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Great Auricular (Neck)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ulnar (Elbow)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Median (Wrist)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Radial Cutaneous (Wrist)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lateral Popliteal (Knee)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Posterior Tibial (Ankle)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

(NE=Normal, E=Enlarged, T=Tender, ET=Both)

Note: Draw Patches and Nodules on Body Diagrams Above. (Label as P=Patch, N=Nodule, I=Infiltration)

#### Sensation Testing

<table>
<thead>
<tr>
<th>Upon Dx</th>
<th>Area</th>
<th>After TC</th>
</tr>
</thead>
<tbody>
<tr>
<td>R</td>
<td></td>
<td></td>
</tr>
<tr>
<td>L</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Eye</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hand</td>
<td></td>
<td></td>
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<tr>
<td>Foot</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

(S=Sensation Intact, L=Loss of Sensation)

#### Muscle Strength Testing

<table>
<thead>
<tr>
<th>Upon Dx</th>
<th>Key Movement</th>
<th>After TC</th>
</tr>
</thead>
<tbody>
<tr>
<td>R</td>
<td></td>
<td></td>
</tr>
<tr>
<td>L</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tight Eye Closure</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Little Finger Out</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Thumb Up</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wrist Up</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Foot Up</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

(S=Strong, W=Weak, P=Paralyzed)

### WHO Disability Grading

Upon Diagnosis

After Treatment Completion (TC)

(Tick the Applicable Block)

### Eye, Hand, and Foot Grading

Upon Diagnosis

After Treatment Completion (TC)

(O=Normal Sensation/Strength, 1=Muscle Weakness and/or Loss of Protective Sensation, 2=Plus Visible Deformities such as Ulcers, Wounds, Clawing, Hand or Foot Drop, Missing or Shortened Fingers or Toes, Lagophthalmos, or Severe Visual Impairment)
Patient Record Card, Page 3

- Treatment Follow-up
- Reaction Follow-up
- Treatment Outcome

<table>
<thead>
<tr>
<th>Tx Mo</th>
<th>Blister Pack #</th>
<th>Date of Visit (MM/DD/YYYY)</th>
<th>Next Pick-up Date (MM/DD/YYYY)</th>
<th># of Doses Missed</th>
<th>Reaction (If Y, see below)</th>
<th>EHF Score</th>
<th>Notes (Travel Plans, Visible Deformities, Explanation of EHF Score Changes, etc.)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td></td>
<td>Y</td>
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<td></td>
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<td>4</td>
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<td>Y</td>
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<td>N</td>
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<td>5</td>
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<td>6</td>
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<td>N</td>
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<td>13</td>
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<td>18</td>
<td></td>
<td>Y</td>
<td></td>
<td></td>
<td>N</td>
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</tr>
</tbody>
</table>

*PB Cases: 6 Blister Packs within 9 Months
MB Cases: 12 Blister Packs within 18 Months

<table>
<thead>
<tr>
<th>Date (MM/DD/YYYY)</th>
<th>Type I</th>
<th>Type II</th>
<th>Symptoms**</th>
<th>EHF Score</th>
<th>Treatment (Prednisone, Clofazimine, etc.)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</tbody>
</table>

**Symptoms (F=Fever, P=Pain, S=Swelling, R=Redness, N=New Lesions, List any Others)

Treatment Outcome

Cured/Treatment Completed:☐ Date:________ Reason:________ Actions Taken (Call, etc.):________
Defaulted:☐ Date:________ Transfer Out:☐ Date:________ Clinic Transferred to:________ Point of Contact:________
Died:☐ Date:________ Reclassified:☐ Date:________ (MM/DD/YYYY)
<table>
<thead>
<tr>
<th>Patient demographics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Initial diagnostic data</td>
</tr>
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</table>

### Patient Registry, Sheet 1

<table>
<thead>
<tr>
<th>Table Headers</th>
</tr>
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<tbody>
<tr>
<td>Civil Status</td>
</tr>
<tr>
<td>M</td>
</tr>
<tr>
<td>NM</td>
</tr>
<tr>
<td>W</td>
</tr>
<tr>
<td>LS</td>
</tr>
<tr>
<td>A</td>
</tr>
<tr>
<td>D</td>
</tr>
<tr>
<td>C</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Place/Address of Birth</th>
<th>Current Address</th>
<th>Name of Treatment Centre</th>
<th>Date of Arrival (MM/DD/YYYY)</th>
<th>Date Diagnosed (MM/DD/YYYY)</th>
<th>Age</th>
<th>Sex (M/F)</th>
<th>Type of Patient</th>
<th>Skin Biopsy</th>
<th>Classification</th>
<th>Total # of Patches</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

**Definition: Name of Treatment Centre**
- M: Married
- NM: Never Married
- W: Widowed
- LS: Legally Separated
- A: Annulled Marriage
- D: Divorced
- C: Common-law Partner

**Code Definition: Type of Patient**
- N: New
- RD: Return after Default
- T: Transfer In
- R: Relapse

**Code Definition: Skin Biopsy**
- ND: Biopsy not performed
- PB: Adult Pauci-bacillary
- MB: Adult Multibacillary
- TT: Tuberculoid
- C: Childhood Pauci-bacillary
- BB: Borderline
- BL: Borderline Lepromatous
- LL: Lepromatous
- O: Other
- Unk: No biopsy pathology report or results lost

**Code Definition: Classification**
- N: No evidence of leprosy
- MB: Adult Multibacillary
- BB: Borderline
- BL: Borderline Lepromatous
- LL: Lepromatous
- O: Other

**Code Definition: Civil Status**
- M: Married
- NM: Never Married
- W: Widowed
- LS: Legally Separated
- A: Annulled Marriage
- D: Divorced
- C: Common-law Partner
## Patient Registry, Sheet 2

- Patient tracking
- Treatment outcome

<table>
<thead>
<tr>
<th>Patient Tracking</th>
<th>Additional Details</th>
<th>Remarks</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient Register Number</td>
<td></td>
<td>HD Coordinator Completing Registry</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Treatment Clinician</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Treatment Partner</td>
</tr>
</tbody>
</table>

### EHF Score

1-12 Each of scores for each eye, hand, or foot with each receiving a 0, 1, or 2 as described below:

1. Normal sensation and strength present
2. Muscle weakness and/or loss of protective sensation present
3. Muscle weakness and/or loss of protective sensation along with visible deformity present

### Date

MM/DD/YYYY All dates in chart should correspond with this pattern

### MDT #

1-12 Blister pack number 1 to 6 for paucibacillary case; blister pack number 1 to 12 for multibacillary case

### Code Definition: EHF Score

1-12 Sum of scores for each eye, hand, or foot with each receiving a 0, 1, or 2 as described above:

- 0: Normal sensation and strength present
- 1: Muscle weakness and/or loss of protective sensation present
- 2: Muscle weakness and/or loss of protective sensation along with visible deformity present

### Code Definition: Date

MM/DD/YYYY All dates in chart should correspond with this pattern

### Code Definition: MDT #

1-12 Blister pack number 1 to 6 for paucibacillary case; blister pack number 1 to 12 for multibacillary case

### Treatment Outcome

**Cured:** Six (6) paucibacillary (PB) MDT blister packs completed within a 9 month period or twelve (12) multibacillary (MB) MDT blister packs completed within an 18 month period as required by WHO

**Defaulted:** Completed less than 6 paucibacillary (PB) blister packs within a 9 month period or less than 12 multibacillary (MB) MDT blister packs within an 18 month period

**Transfer out:** Transferred or relocated to another reporting unit for continuation of treatment

**Died:** Died for any reason during treatment

**Reclassified:** A patient who was previously diagnosed as having paucibacillary or multibacillary disease and now is diagnosed as having the other disease type based on pathology examination of biopsy

### Code Definition: Treatment Outcome

- C Cured:
- DF Defaulted:
- TO Transfer out:
- D Died:
- R Reclassified:

### Code Definition: Method of Treatment

- DOT Directly Observed
- AMDT Accompanied MDT
- SAT Self-administered
- Both Both DOT and SAT
### Household Contact Examination

<table>
<thead>
<tr>
<th>Name</th>
<th>Age</th>
<th>Relationship</th>
<th>Year</th>
<th>Date of Exam</th>
<th>Results</th>
<th>Remarks</th>
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<tr>
<td>New Jane</td>
<td>40</td>
<td>Spouse</td>
<td>Y1</td>
<td>1/1/2012</td>
<td>Negative</td>
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<tr>
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<tr>
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Name: Smith, John  
Date of Birth:  
Leprosy Case Number: 2012-FM-HD-KSA-001  
Case Status: 

Hansen’s Disease Module, Page 2
Hansen’s Disease Module, Page 3

- Body Chart
  - Patches
  - Nodules
  - Infiltrations
Hansen’s Disease Module, Page 4

- Nerve Function Assessment
- Nerve Exam
- Sensation Testing
- Muscle Strength Testing
Hansen’s Disease Module, Page 5

- WHO Disability Grading
- Eye, Hand, and Foot Grading
- Slit Skin Smear
- Biopsy
- Treatment/Reaction Follow-up
- Treatment Outcome
3.1 How should case detection be organized?

1. “Active case-finding methods, including large-scale campaigns, are generally not recommended as these have become less and less effective”

2. “The use of small-scale campaigns should be restricted to special situations or for exceptional circumstances”

3. “It should be a one-time activity with the principal aim of establishing sustainable services”
Future Plans

- **Evaluate new surveillance measures**
- **Address training gaps**
  - Disability management
  - Train-the-trainer templates
  - Public health messaging
  - Health care system integration
    - Physicians
    - Nurses
- **Assess training and communication messaging**
- **Evaluate patient management**