**Case report form:** Eumycetoma

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**Patient demographic characteristics**

Unique patient ID: \_\_\_\_\_\_\_\_\_\_\_ (site\_####)

Site submitting case: \_\_\_\_\_\_\_\_\_\_\_

Location of residence for patient (ZIP Code): \_\_\_\_\_\_\_\_\_\_\_\_\_ OR [] Unknown

Age at diagnosis (years): \_\_\_\_\_\_\_\_\_\_\_\_

Sex: [] Male [] Female

Race and/or ethnicity (select all that apply and enter additional details in the spaces provided):

[] American Indian or Alaska Native

*Enter, for example, Navajo Nation, Blackfeet Tribe of the Blackfeet Indian Reservation of Montana, Native Village of Barrow Inupiat Traditional Government, Nome Eskimo Community, Aztec, Maya, etc.*

[] Asian – provide details below

[] Chinese [] Asian Indian [] Filipino [] Vietnamese [] Korean [] Japanese

*Enter, for example, Pakistani, Hmong, Afghan, etc.*

[] Black or African American – provide details below

[] African American [] Jamaican [] Haitian [] Nigerian [] Ethiopian [] Somali

*Enter, for example, Trinidadian and Tobagonian, Ghanaian, Congolese, etc.* \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

[] Hispanic or Latino – provide details below

[] Mexican [] Puerto Rican [] Salvadoran [] Cuban [] Dominican [] Guatemalan

*Enter, for example, Colombian, Honduran, Spaniard, etc.* \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

[] Middle Eastern or North African – provide details below

[] Lebanese [] Iranian [] Egyptian [] Syrian [] Iraqi [] Israeli

*Enter, for example, Moroccan, Yemeni, Kurdish, etc.* \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

[] Native Hawaiian or Pacific Islander – provide details below

[] Native Hawaiian [] Samoan [] Chamorro [] Tongan [] Fijian [] Marshallese

*Enter, for example, Chuukese, Palauan, Tahitian, etc.* \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

[] White – provide details below

[] English [] German [] Irish [] Italian [] Polish [] Scottish

*Enter, for example, French, Swedish, Norwegian, etc.* \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Monthly household income (USD) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Occupation at time of presumed infection: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Industry at time of presumed infection: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

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**Underlying medical conditions (active or present in the 2 years before symptom onset)**

Diabetes mellitus [] Yes [] No [] Unknown

Chronic kidney disease [] Yes [] No [] Unknown

If yes, on dialysis? [] Yes [] No [] Unknown

If yes, GFR < 60? [] Yes [] No

Liver cirrhosis? [] Yes [] No [] Unknown

Chronic hepatitis without cirrhosis? [] Yes [] No [] Unknown

If yes, [] Hep B [] Hep C

Immunocompromising condition [] Yes [] No [] Unknown

[] HIV infection

[] HIV infection without AIDS (CD4 ≥ 200)

[] HIV infection with AIDS (CD4 < 200) or chart diagnosis of advanced HIV disease

[] Cancer diagnosis, specify \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

[] On chemotherapy, specify \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Date of cancer diagnosis (mm/dd/yyyy): \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

[] Transplant

[] Solid organ, specify organ \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

[] Hematologic (stem cell)

Date of transplantation (mm/dd/yyyy): \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

[] Immunosuppressive therapy, specify \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

[] Other immunocompromised condition, specify \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Other major underlying condition not listed (specify): \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

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**Exposure** **history**

Has patient traveled or lived internationally in their life? [] Yes [] No [] Unknown

* + Country 1 \_\_\_\_\_\_\_\_\_\_\_\_; Approximate duration of stay (years):
  + Country 2 \_\_\_\_\_\_\_\_\_\_\_\_; Approximate duration of stay (years):
  + Country 3 \_\_\_\_\_\_\_\_\_\_\_\_; Approximate duration of stay (years):
  + Country 4 \_\_\_\_\_\_\_\_\_\_\_\_; Approximate duration of stay (years):
  + Country 5 \_\_\_\_\_\_\_\_\_\_\_\_; Approximate duration of stay (years):

Did the patient immigrate to the United States? [] Yes [] No [] Unknown

If yes, date of immigration (mm/dd/yyyy): \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

If yes, country immigrated from: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Any traumatic inoculation ever recalled? [] Yes [] No [] Unknown

If yes, please describe geographic location (e.g., city, state): \_\_\_\_\_\_\_\_\_\_\_\_\_\_

If yes, please describe the material involved (e.g., thorns, branches): \_\_\_\_\_\_\_\_\_

If yes, please describe any weather events (e.g., hurricane, flood): \_\_\_\_\_\_\_\_\_\_\_\_

If yes, please indicate approximate date of traumatic inoculation (mm/dd/yyyy): \_\_\_\_\_\_\_\_\_\_\_\_\_

Most likely source of infection, according to clinician \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

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**Diagnosis**

Did patient have health care facility visits (health center, hospital, etc.) for mycetoma symptoms before visit with mycetoma diagnosis? [] Yes [] No [] Unknown

If yes, how many visits? \_\_\_\_\_\_\_\_\_\_\_\_

Were there misdiagnoses before being diagnosed with mycetoma [] Yes [] No [] Unknown

What misdiagnoses, if any, did this patient have before being diagnosed with mycetoma (in the last 12 months):

* Please list all misdiagnoses: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**Laboratory testing (associated with diagnosis)**:

[] X-ray [] Not performed [] Unknown if performed

date of imaging: \_\_\_\_\_\_\_\_\_\_\_\_; result: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

[] MRI [] Not performed [] Unknown if performed

date of imaging: \_\_\_\_\_\_\_\_\_\_\_\_; result: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

[]Ultrasound imaging [] Not performed [] Unknown if performed

date of imaging (mm/dd/yyyy): \_\_\_\_\_\_\_\_\_\_\_\_; result: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

[]CT Scan [] Not performed [] Unknown if performed

date of imaging (mm/dd/yyyy): \_\_\_\_\_\_\_\_\_\_\_\_; result: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

[]Histopathology [] Not performed [] Unknown if performed

date (mm/dd/yyyy): \_\_\_\_\_\_\_\_\_\_\_\_; type of stain: \_\_\_\_\_\_\_\_\_\_

result: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

[]Cytology [] Not performed [] Unknown if performed

date (mm/dd/yyyy): \_\_\_\_\_\_\_\_\_\_\_\_; result: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

[] Fungal grain culture [] Not performed [] Unknown if performed

date of collection (mm/dd/yyyy): \_\_\_\_\_\_\_\_\_\_\_\_; Positive/Negative: \_\_\_\_\_\_\_\_\_\_\_\_\_ Organism(s): \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_;

[] Broad range sequencing [] Not performed [] Unknown if performed

date of collection (mm/dd/yyyy): \_\_\_\_\_\_\_\_\_\_\_\_; Type (e.g., 18s, ITS): \_\_\_\_\_\_\_\_\_\_\_\_

Positive/Negative: \_\_\_\_\_\_\_\_\_\_\_\_\_ Organism(s): \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_;

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**Signs and symptoms noted during patient interview**:

|  |  |  |
| --- | --- | --- |
| Signs & Symptoms | Yes/No | Onset Date if Known |
| Localized swelling |  |  |
| Openings on the skin (sinuses) |  |  |
| Discharge containing grains |  |  |
| Macroscopic grain size |  |  |
| Microscopic grain size |  |  |
| Lymph node involvement |  |  |
| Bone involvement |  |  |
| Pain |  |  |
| Itching |  |  |
| Other symptoms, please describe:\_\_\_\_\_\_\_ |  |  |

Please describe the specific location on the body of the mycetoma lesion(s) (please mark all that apply for multiple areas affected):

[] Head and neck

[] Trunk

[] Upper limbs

[] Buttocks, perineum, genitals

[] Lower limbs

Additional comments on anatomical location: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Clinical size of mycetoma lesion: Length (cm): \_\_\_\_\_\_\_\_\_\_\_\_\_\_; Width (cm):\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Color of grains:

[] Black

[] White/yellow

[] Red

[] No visible grains

Did mycetoma cause any form of disability: [] Yes [] No [] Unknown

If yes, please fill out the table below:

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Disability | Yes/No | Onset Date | Number of days with disability | Inability to work (Y/N) |
| Mild motor impairment (has some difficulty in moving around but is able to walk without help) |  |  |  |  |
| Moderate motor impairment (has some difficulty in moving around, and difficulty in lifting and holding objects, dressing and sitting upright, but is able to walk without help) |  |  |  |  |
| Severe motor impairment (is unable to move around without help, and is not able to lift or hold objects, get dressed or sit upright) |  |  |  |  |

**Treatment**

Was the patient treated for eumycetoma?

[] Yes [] No [] Unknown

**If yes**, list all therapeutic agents (e.g., antifungals, immune response modulators, antibiotics, steroids) in the table below:

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
| Therapeutic Agent Name | Max Daily dose (mg/day) | Route (e.g., IV, PO, IT) | Start Date | Duration  of Therapy | Therapy ongoing  at time of  abstraction | Discontinued due to toxicity. **If yes, describe toxicity** | Therapeutic Drug Monitoring (e.g., serum level of antifungal) |
|  |  |  | \_\_\_ / \_\_\_ / \_\_\_\_\_\_ | \_\_\_\_\_days | [] Yes [] No | [] Yes [] No  ---------------------  --------------------- | [] Yes [] No  Level 1:  Date:  Value:  Level 2:  Date:  Value |
|  |  |  | \_\_\_ / \_\_\_ / \_\_\_\_\_\_ | \_\_\_\_\_days | [] Yes [] No | [] Yes [] No  ---------------------  --------------------- | [] Yes [] No  Level 1:  Date:  Value:  Level 2:  Date:  Value |
|  |  |  | \_\_\_ / \_\_\_ / \_\_\_\_\_\_ | \_\_\_\_\_days | [] Yes [] No | [] Yes [] No  ---------------------  --------------------- | [] Yes [] No  Level 1:  Date:  Value:  Level 2:  Date:  Value |
|  |  |  | \_\_\_ / \_\_\_ / \_\_\_\_\_\_ | \_\_\_\_\_days | [] Yes [] No | [] Yes [] No  ---------------------  --------------------- | [] Yes [] No  Level 1:  Date:  Value:  Level 2:  Date:  Value |
|  |  |  | \_\_\_ / \_\_\_ / \_\_\_\_\_\_ | \_\_\_\_\_days | [] Yes [] No | [] Yes [] No  ---------------------  --------------------- | [] Yes [] No  Level 1:  Date:  Value:  Level 2:  Date:  Value |
|  |  |  | \_\_\_ / \_\_\_ / \_\_\_\_\_\_ | \_\_\_\_\_days | [] Yes [] No | [] Yes [] No  ---------------------  --------------------- | [] Yes [] No  Level 1:  Date:  Value:  Level 2:  Date:  Value |

Notes about treatment: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Did the patient undergo local surgical excision of the eumycetoma lesions: [] Yes [] No [] Unknown

If yes, date of surgical excision (mm/dd/yyyy): \_\_\_\_\_\_\_\_\_\_\_\_\_

Did the patient receive antimicrobials before local surgical excision? [] Yes [] No [] Unknown

Did the patient undergo regular debridement: [] Yes [] No [] Unknown

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**Complications**:

|  |  |  |  |
| --- | --- | --- | --- |
| Outcome | Yes/No | Onset Date | Notes (e.g., location) |
| Tissue fibrosis |  |  |  |
| Ankylosis (abnormal stiffening and immobility of a joint due to fusion of the bones) |  |  |  |
| Massive destruction of a joint |  |  |  |
| Pulmonary eumycetoma due to secondary spread from a subcutaneous lesion |  |  |  |
| Bronchopleural cutaneous fistula |  |  |  |
| Secondary bacterial infection |  |  |  |
| Amputation |  |  |  |
| Lymphedema |  |  |  |
| Other; specify \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ |  |  |  |

Did the mycetoma infection resolve (clinical and radiographic cure)? [] Yes [] No [] Unknown

If yes, what was the date of clinical resolution:

If no, what was date of last follow-up (mm/dd/yyyy):

Did this patient die within 2 years after the mycetoma diagnosis? [] Yes [] No [] Unknown

If yes, was mycetoma a contributing factor in patient’s death? [] Yes [] No [] Unknown

Additional comments: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**Appendix 2: Dermatology Life Quality Index Tool**

Dermatology Life Quality Index Questionnaire:

1. Over the last week, how itchy, sore, painful, or stinging has your skin problem been?
   1. Very much
   2. A lot
   3. A little
   4. Not at all
2. Over the last week, how embarrassed or self-conscious have you been because of your skin problem?
   1. Very much
   2. A lot
   3. A little
   4. Not at all
3. Over the last week, how much has your skin problem interfered with you going shopping or looking after your home or garden?
   1. Very much
   2. A lot
   3. A little
   4. Not at all
   5. Not relevant
4. Over the last week, how much has your skin problem influenced the clothes you wear?
   1. Very much
   2. A lot
   3. A little
   4. Not at all
   5. Not relevant
5. Over the last week, how much has your skin problem affected any social or leisure activities?
   1. Very much
   2. A lot
   3. A little
   4. Not at all
   5. Not relevant
6. Over the last week, how much has your skin problem made it difficult for your to do any sport?
   1. Very much
   2. A lot
   3. A little
   4. Not at all
   5. Not relevant
7. Over the last week, has your skin problem prevented you from working or studying
   1. Yes
   2. No
   3. Not relevant
      1. If no, over the last week how much has your skin problem been a problem at work or studying?
         1. A lot
         2. A little
         3. Not at all
8. Over the last week, how much has your skin problem created problems with your partner or any of your close friends or relatives?
   1. Very much
   2. A lot
   3. A little
   4. Not at all
   5. Not relevant
9. Over the last week, how much has your skin problem caused any sexual difficulties?
   1. Very much
   2. A lot
   3. A little
   4. Not at all
   5. Not relevant
10. Over the last week, how much of a problem has the treatment for your skin problem been, for example by making your home messy, or by taking up time?
    1. Very much
    2. A lot
    3. A little
    4. Not at all
    5. Not relevant