Instructions for Completing the AFM Patient Summary Form

GENERAL. Clinicians should remain vigilant and send information to their state or local health department for all patients that meet the clinical and laboratory/imaging criteria for AFM (as highlighted on page 3).

   a. Clinicians should send information about patients who meet the clinical and laboratory/imaging criteria regardless of any laboratory results.

   b. The AFM *Patient Summary Form* should be completed by the state or local health department, in conjunction with a clinician who provided care to the patient during the neurologic illness.

CDC requests that state health departments send the *Patient Summary Form,* along with the MRI report and images, to CDC for case classification and to help monitor these cases at the national level. AFM neurology experts will classify cases meeting the criteria for AFM according to the Council of State and Territorial Epidemiologists (CSTE) AFM case definition using the *Patient Summary Form*, MRI report, and MRI images. When sending this information, please indicate the information included with the *Patient Summary Form* in the box at the top of the form.

Demographics

1. **TODAY'S DATE.** Date that the patient summary form is initiated.
2. **STATE ASSIGNED ID**. Alpha/numeric
3. **SEX**. Indicate whether the patient is male or female.
4. **DATE OF BIRTH**. Patient birth date.
5. **RESIDENCE.** State in which patient resides.
6. **COUNTY.** County in which patient resides.
7. **RACE.** Self-reported race of patient; more than one option may be reported.
8. **ETHNICITY.** Self-reported ethnicity of patient.
9. **DATE OF ONSET OF LIMB WEAKNESS.** Indicate the date of limb weakness onset of patient.
10. **PATIENT ADMITTED TO HOSPITAL.** Was the patient admitted to a hospital?
11. **DATE OF ADMISSION TO FIRST HOSPITAL.** Date the patient was <u>FIRST</u> hospitalized.
12. **DATE OF DISCHARGE FROM LAST HOSPITAL.** Date the patient was discharged from LAST hospital (if patient is still hospitalized, check box for "still hospitalized at time of form submission").
13. **PATIENT DIED FROM THIS ILLNESS.** Did the patient die from this illness?
14. **DATE OF DEATH.** If the patient died from this illness, indicate the date of death.

Signs/symptoms/condition at ANY time during the illness

15. **WEAKNESS.** Specify for each limb (arms and/or legs) if there was noted acute onset of weakness.

   15a. **TONE IN AFFECTED LIMB.** Specify for each limb (arms and/or legs) the tone in the limb with weakness (select one option per limb) – *this question is used as a screening tool for the classification process so please ensure this question is complete*

16. **PATIENT ADMITTED TO ICU.** Was the patient admitted to the ICU?
17. **DATE ADMITTED TO ICU.** If the patient was admitted to ICU, indicate date of admission.

18. **PATIENT HAS RESPIRATORY ILLNESS.** Did the patient have a respiratory illness within the 4-week period before onset of limb weakness?
19. **RESPIRATORY ILLNESS ONSET DATE.** If the patient has respiratory illness, indicate onset date.
20. **PATIENT HAS GASTROINTESTINAL ILLNESS.** Did the patient have a gastrointestinal illness (e.g., diarrhea or vomiting) within the 4-week period before onset of limb weakness?
21. **GASTROINTESTINAL ILLNESS ONSET DATE.** If the patient has gastrointestinal illness, indicate onset date.
22. **PATIENT HAS FEVER.** Did the patient have a fever (≥38°C/100.4°F), measured by parent or provider, within the 4-week period before onset of limb weakness?
23. **FEVER ONSET DATE.** If the patient has fever, indicate onset date.
24. **PATIENT HAS PAIN IN NECK OR BACK.** Did the patient have pain in their neck or back within the 4-week period before onset of limb weakness?
25. **PAIN ONSET DATE.** If the patient has pain in neck or back, indicate onset date.
26. **PATIENT HAS UNDERLYING ILLNESSES.** Does the patient have any underlying illnesses other than the presenting illness?
27. **IF YES, LIST.** List the patient's underlying illness(es).

Magnetic Resonance Imaging

28. **MRI OF SPINAL CORD PERFORMED.** Indicate whether the patient had an MRI of the spinal cord performed.
29. **DATE SPINAL MRI PERFORMED.** If a spinal MRI was performed, indicate date of the spinal cord MRI.
30. **SPINAL MRI SHOWS LESION IN AT LEAST SOME SPINAL CORD GRAY MATTER.** Indicate whether the patient's spinal MRI shows lesions in at least some of the spinal cord gray matter (*this is used as a screening tool for the classification process so please ensure this question is complete*)
31. **MRI OF BRAIN PERFORMED.** Indicate whether the patient had an MRI of the brain performed.
32. **DATE BRAIN MRI PERFORMED.** If a brain MRI was performed, indicate date of the brain MRI.

CSF examination

33. **LUMBAR PUNCTURE PERFORMED.** Indicate if there was a CSF examination done (option for including up to two exams. If more than 2 CSF examinations performed, list the first 2 performed).
    32a. **CSF from LP1.**
    - **Date of first lumbar puncture**: Indicate the date of the first lumbar puncture performed.
    - **WBC/mm³:** Indicate the white blood cell count for the first lumbar puncture.
    - **% neutrophils:** Indicate the % neutrophils for the first lumbar puncture.
    - **% lymphocytes:** Indicate the % lymphocytes for the first lumbar puncture.
    - **% monocytes:** Indicate the % monocytes for the first lumbar puncture.
    - **% eosinophils:** Indicate the % eosinophils for the first lumbar puncture.
    - **RBC/mm³:** Indicate the red blood cell count for the first lumbar puncture.
    - **Glucose mg/dl:** Indicate the glucose level for the first lumbar puncture.
    - **Protein mg/dl:** Indicate the protein level for the first lumbar puncture.
    32b. **CSF from LP2.**
    - **Date of second lumbar puncture**: Indicate the date of the second lumbar puncture performed.

- **WBC/mm³:** Indicate the white blood cell count for the <u>second</u> lumbar puncture.
- **% neutrophils:** Indicate the % neutrophils for the <u>second</u> lumbar puncture.
- **% lymphocytes:** Indicate the % lymphocytes for the <u>second</u> lumbar puncture.
- **% monocytes:** Indicate the % monocytes for the <u>second</u> lumbar puncture.
- **% eosinophils:** Indicate the % eosinophils for the <u>second</u> lumbar puncture.
- **RBC/mm³:** Indicate the red blood cell count for the <u>second</u> lumbar puncture.
- **Glucose mg/dl:** Indicate the glucose level for the <u>second</u> lumbar puncture.
- **Protein mg/dl:** Indicate the protein level for the <u>second</u> lumbar puncture.

Acute Flaccid Myelitis Outcome

Follow-up of confirmed and probable AFM cases, conducted at 60 days, 6 months, AND 12 months after onset of limb weakness, will help us understand long-term outcomes for patients with AFM. Follow-up should be done by contacting the patient/family for answers to the questions, or if that is not possible, by contacting the patient's regular healthcare provider.

At the time of the 60-day follow-up, the following additional information should be collected and sent to CDC to ensure that complete information on the acute phase of illness is collected for the confirmed and probable cases. The information to collect includes: discharge summary, history and physical notes, neurology consult notes, infectious disease consult notes (if available), EMG report (if performed), vaccination record from state vaccine registry, and diagnostic laboratory results. Please check the boxes to indicate what information is available.

33. **DATE OF FOLLOW-UP.** Indicate the date of follow-up with the patient.

34. **IMPAIRMENT.** Indicate if the patient has any lasting physical effects or residual impairment from AFM. If yes, select the answer that best describes the impairment.
35. **PHYSICAL CONDITION.** Indicate the answer that best describes how frequently the patient needs medical, nursing care, or physical therapy.
36. **UPPER LIMB FUNCTION.** For activities that mainly depend on the upper limbs or arms, indicate the answer that best describes the patient's current ability to do self-care activities appropriate for their age, such as drinking, eating, getting dressed, brushing teeth and washing.
37. **LOWER LIMB FUNCTION.** For activities that mainly depend on the lower limbs or legs, indicate the answer that best describes the patient's current mobility appropriate for their age, i.e., their ability to walk, climb stairs, and transfer to a chair/toilet/tub or shower.
38. **SENSORY COMPONENTS.** Indicate the answer that best describes the patient's ability to communicate, specifically speech, hearing, and vision.
39. **EXCRETORY FUNCTIONS.** Indicate the answer that best describes the patient's ability to perform independent toileting that is appropriate for his/her age.
40. **SUPPORT FACTORS.** For support that the patient needs to perform tasks appropriate for their age, indicate the answer that best describes the patient.

In June 2015, the Council of State and Territorial Epidemiologists (CSTE) adopted a standardized case definition for AFM that is used by CDC to classify suspected cases as confirmed or probable. The case definition was updated in June 2017 and again in June 2019. The most updated version is presented below.

Acute Flaccid Myelitis case definition
 (https://cdn.ymaws.com/www.cste.org/resource/resmgr/2019ps/final/19-ID-05_AFM_final_7.31.19.pdf)

Clinical Criteria
- An illness with onset of acute flaccid* limb weakness

Laboratory/Imaging Criteria
- A magnetic resonance image (MRI) showing spinal cord lesion in at least some gray matter† and spanning one or more spinal segments, AND
- Excluding persons with gray matter lesions† in the spinal cord resulting from physician diagnosed malignancy, vascular disease, or anatomic abnormalities.

Case Classification
Confirmed:
- An illness with onset of acute flaccid* limb weakness AND
- MRI showing spinal cord lesion largely restricted to gray matter† and spanning one or more spinal segments
    - Excluding persons with gray matter lesions† in the spinal cord resulting from physician diagnosed malignancy, vascular disease, or anatomic abnormalities AND
    - Absence of a clear alternative diagnosis attributable to a nationally notifiable condition

Probable:
- An illness with onset of acute flaccid* limb weakness AND
- MRI showing spinal cord lesion where gray matter involvement† is present but predominance cannot be determined,
    - Excluding persons with gray matter lesions† in the spinal cord resulting from physician diagnosed malignancy, vascular disease, or anatomic abnormalities AND
    - Absence of a clear alternative diagnosis attributable to a nationally notifiable condition

Suspect:
- An illness with onset of acute flaccid* limb weakness AND
- MRI showing spinal cord lesion in at least some gray matter† and spanning one or more spinal segments,
    - Excluding persons with gray matter lesions† in the spinal cord resulting from physician diagnosed malignancy, vascular disease, or anatomic abnormalities AND
    - Available information is insufficient to classify case as probable or confirmed, AND
    - Absence of a clear alternative diagnosis attributable to a nationally notifiable condition.

* Low muscle tone, limp, hanging loosely, not spastic or contracted.
† Terms in the spinal cord MRI report such as "affecting mostly gray matter," "affecting the anterior horn or anterior horn cells," "affecting the central cord," "anterior myelitis," or "poliomyelitis" would all be consistent with this terminology.

Comment

To provide consistency in case classification, review of case information and assignment of final case classification for all suspected AFM cases will be done by experts in national AFM surveillance. This is similar to the review required for final classification of paralytic polio cases.