

Instructions for Completing the AFM Patient Summary Form

GENERAL. Clinicians should report all patients who meet the case definition (as specified on page 4) for AFM to their state or local health department using this *Patient Summary Form*.

- a. Clinicians should report patients who meet the case definition regardless of any laboratory results.
- b. This form should be completed by, or in conjunction with, a clinician who provided care to the patient during the neurologic illness.
- c. So that cases can be monitored in as real time as possible, this form should be submitted to the state or local health department as soon as possible after case identification.

CDC requests that state health departments also submit the *Patient Summary Form* to CDC to help monitor these cases at the national level. A form that is largely complete but has some information pending (e.g., hospital or health department laboratory results) or under investigation (e.g., polio vaccination history) should still be submitted as soon as possible, and the pending results can then be provided to CDC when they become available.

Demographics

1. **TODAY'S DATE.** Date that clinician is initiating completing the patient summary form.
2. **STATE ASSIGNED ID.** Alpha/numeric
3. **SEX.** Indicated whether the case-patient is male or female.
4. **DATE OF BIRTH.** Case-patient birth date.
5. **RESIDENCE.** State in which case-patient resides.
6. **COUNTY.** County in which case-patient resides.
7. **RACE.** Self-reported race of case-patient; more than one option may be reported.
8. **ETHNICITY.** Self-reported ethnicity of case-patient.
9. **DATE OF ONSET OF LIMB WEAKNESS.** Limb weakness onset date of case-patients.
10. **HOSPITALIZED?** Was case-patient hospitalized?
11. **DATE HOSPITALIZED.** Date case-patient FIRST hospitalized.
12. **DATE DISCHARGED.** Date case-patient discharged from LAST hospital (indicate if still hospitalized).
13. **DIED?** Did case-patient die from this illness?
14. **DATE OF DEATH.** Case-patient's date of death.

Signs/symptoms/condition at ANY time during the illness

If the answer to a question is truly UNKNOWN or no information is recorded in the medical record (NOT RECORDED or NR) then check the UNK/NR box, otherwise, leave answer blank.

15. **WHICH LIMBS HAVE BEEN ACUTELY WEAK?** Specify any/all limbs (arms and or legs) for which there was noted acute onset of focal weakness.
16. **DATE OF NEUROLOGIC EXAM.** The neurologic examination date recorded at most severe weakness to that point.

17. **REFLEXES IN THE AFFECTED LIMB(S).** Numeric value assigned to reflexes in affected limb(s) recorded at the most severe weakness to that point.
18. **SENSORY LOSS/NUMBNESS?** Has case-patient experienced any sensory loss or numbness in the affected limb(s) at any time during the illness?
19. **BURNING PAIN?** Has case-patient experienced any burning pain in the affected limb(s) at any time during the illness?
20. **SENSORY LEVEL ON THE TORSO?** Has case-patient experienced reduced sensation below a certain level below the torso at any time during the illness?
21. **CRANIAL NERVE FEATURES.** Did case-patient have any cranial nerve features? If YES, indicate the type experienced by the case-patient.
22. **BOWEL OR BLADDER INCONTINENCE?** Has case-patient experienced at any time during the illness bowel or bladder incontinence?
23. **CHANGE IN MENTAL STATUS?** Has case-patient experienced at any time during the illness a change in mental status?
24. **SEIZURES?** Has case-patient experienced any seizures at any time during the illness?
25. **RECEIPT OF POSITIVE PRESSURE VENTILATION?** Has case-patient received positive pressure ventilation, including invasive or non-invasive ventilation and BiPAP or CPAP?

Other patient information

26. **RESPIRATORY ILLNESS?** Did case-patient have a respiratory illness within the 4-week period before onset of limb weakness?
27. **RESPIRATORY ILLNESS ONSET DATE.** Case-patient's respiratory onset date.
28. **GASTROINTESTINAL ILLNESS?** Did case-patient have a gastrointestinal illness (e.g., diarrhea or vomiting) within the 4-week period before onset of limb weakness?
29. **GASTROINTESTINAL ILLNESS ONSET DATE.** Case-patient's gastrointestinal illness onset date.
30. **RASH?** Did case-patient have a new onset rash within the 4-week period before onset of limb weakness?
31. **RASH ONSET DATE.** Case-patient's rash onset date.
32. **FEVER?** Did case-patient have a fever ($\geq 38^{\circ}\text{C}/100.4^{\circ}\text{F}$), measured by parent or provider, within the 4-week period before onset of limb weakness?
33. **FEVER ONSET DATE.** Case-patient's fever onset date.
34. **IMMUNOSUPPRESSING AGENTS?** Did case-patient receive any immuno-suppressing agents within the 4-week period before onset of limb weakness?
35. **IF YES, LIST.** If any, list the date medication first administered, name of medication, how administered, and the dosage, duration, and overall amount received by case-patient.
36. **TRAVEL OUTSIDE U.S.?** Did case-patient travel outside the U.S. within the 4-week period before onset of limb weakness?
37. **IF YES, LIST.** If any, list the country(s) visited by the case-patient.
38. **UNDERLYING ILLNESSES?** Does the case-patient have any underlying illnesses?
39. **IF YES, LIST.** List the case-patient's underlying illness(es).
40. **FEVER ON DAY OF LIMB WEAKNESS ONSET?** Did the case-patient experience a fever (see definition in 32.) on the day of onset of limb(s) weakness?

Polio vaccination history

41. **IPV DOSES?** Indicate, if known, the number of documented inactivated polio vaccine doses received by the case-patient before the onset of limb weakness.
42. **OPV DOSES?** Indicate, if known, the number of documented oral polio vaccine doses received by the case-patient before the onset of limb weakness.
43. **DOCUMENTED POLIO VACCINE DOSES IF TYPE UNKNOWN?** If type of vaccine not known, indicate the total number of documented polio vaccine doses received by case-patient before the onset of weakness.

Neuroradiographic findings

44. **MRI OF SPINAL CORD PERFORMED?** Indicate whether case-patient had an MRI of the spinal cord performed.
45. **IF YES, NUMBER OF SPINAL MRIs PERFORMED.** If case-patient had spinal MRI performed, indicate the number of documented spinal MRIs performed.
For questions 46-71, complete based on results from the most abnormal MRI.
46. **DATE OF STUDY.** Date of the most abnormal MRI of the case-patient's spinal cord.
47. **LEVELS IMAGED.** Indicate the spinal cord levels imaged by MRI.
48. **LOCATION OF LESIONS.** Indicate the location of spinal cord lesions.
49. **CERVICAL CORD LEVEL.** Indicate whether the cervical level was affected.
50. **THORACIC CORD LEVEL.** Indicate whether the thoracic level was affected.
51. **AREAS OF SPINAL CORD AFFECTED.** For cervical and thoracic levels, indicate what spinal cord areas were affected.
52. **CORD EDEMA.** Was there cord edema?
53. **GADOLINIUM USED?** Was gadolinium used with the spinal cord MRI? *If NO, skip to question 59.*
54. **GRAY MATTER LESIONS.** For cervical/thoracic cord or conus lesions if gadolinium used, was there enhancement of any gray matter lesions?
55. **WHITE MATTER LESIONS.** For cervical/thoracic cord or conus lesions if gadolinium used, was there enhancement of any white matter lesions?
56. **CERVICAL/THORACIC NERVE ROOTS.** For cervical/thoracic cord or conus lesions if gadolinium used, was there enhancement of any cervical/thoracic nerve roots?
57. **VENTRAL NERVE ROOTS.** For cauda equina lesions if gadolinium used, was there enhancement of the ventral nerve roots?
58. **DORSAL NERVE ROOTS.** For cauda equina lesions if gadolinium used, was there enhancement of the dorsal nerve roots?
59. **BRAIN MRI PERFORMED.** Indicate whether case-patient had a brain/brainstem/cerebellum MRI performed.
If NO, skip to question 72.
60. **DATE OF STUDY.** Date of the MRI of the case-patient's brain.
61. **SUPRATENTORIAL LESIONS.** Were there any supratentorial lesions identified with the brain MRI?
62. **IF YES, INDICATE LOCATION.** Indicate location of supratentorial lesions identified with the brain MRI.
63. **BRAINSTEM LESIONS.** Were there any brainstem lesions identified with the brain MRI?
64. **IF YES, INDICATE LOCATION.** Indicate location of brainstem lesions identified with the brain MRI.

65. **CRANIAL NERVE LESIONS.** Were there any cranial nerve lesions identified with the brain MRI?
66. **IF YES, INDICATE CRANIAL NERVES.** Indicate in which cranial nerve(s) lesions were detected with the brain MRI.
67. **CEREBELLUM LESIONS.** Were there any lesions detected in the cerebellum?
68. **GADOLINIUM USED?** Was gadolinium used with the brain MRI? *If NO, skip to question 72.*
69. **SUPRATENTORIAL LESIONS.** If gadolinium used, was there enhancement of any supratentorial lesions?
70. **BRAINSTEM LESIONS.** If gadolinium used, was there enhancement of any brainstem lesions?
71. **CRANIAL NERVE LESIONS.** If gadolinium used, was there enhancement of any cranial nerve lesions?
72. **EMG DONE?** Indicate if an EMG was performed and if so, indicate the date.
73. **IF YES, ACUTE MOTOR NEUROPATHY?** If yes an EMG was done, was there evidence of acute motor neuropathy, motor neuropathy, motor nerve or anterior horn cell involvement?
74. **LUMBAR PUNCTURE PERFORMED?** Indicate if there was a CSF examination done (option for up to two. If more than 2 CSF examinations performed, list the first 2 performed).
 - 67a. **CSF from LP1.** Complete findings for lumbar puncture 1.
 - 67b. **CSF from LP2.** Complete findings for lumbar puncture 1.
75. **WAS CSF TESTED?** Complete information for CSF specimen testing for any of the pathogens listed, test type, test results, whether specimen was typed, and type if known. Provide information for the EARLIEST specimen collected if more than one CSF specimen collected and tested.
76. **WAS A RESPIRATORY TRACT SPECIMEN TESTED?** Complete information for respiratory tract specimen testing for any of the pathogens listed, test type, test results, whether specimen was typed, and type if known. Provide information for the EARLIEST specimen collected if more than one respiratory specimen collected and tested.
77. **WAS A STOOL SPECIMEN TESTED?** Complete information for stool specimen testing for any of the pathogens listed, test type, test results, whether specimen was typed, and type if known. Provide information for the EARLIEST specimen collected if more than one stool specimen collected and tested.
78. **WAS SERUM TESTED?** Complete information for serum specimen testing for any of the pathogens listed, test type, and test results. Provide information for the EARLIEST specimen collected if more than one serum specimen collected and tested.
79. **SPECIFIC ETIOLOGY?** Was/Is a specific etiology considered to be the most likely cause for the patient's neurological illness?
80. **IF YES, LIST.** List the etiology determined and reason(s) for considering it the most likely cause for the case-patient's neurological illness.
81. **SPECIMENS TO CDC.** If case-patient classified as confirmed or probable, will clinical specimens be sent to CDC for testing?
82. **SPECIMEN TYPES TO CDC.** If yes, indicate the specimen type(s) that will be sent to CDC.

Case Definition

In June 2015, the Council of State and Territorial Epidemiologists (CSTE) adopted a [standardized case definition for acute flaccid myelitis\[6 pages\]](#). As of August 1, 2015, a patient must meet the CSTE clinical criteria below to be considered either a confirmed or probable case of acute flaccid myelitis:

Acute Flaccid Myelitis case definition:

(<http://c.ymcdn.com/sites/www.cste.org/resource/resmgr/2015PS/2015PSFinal/15-ID-01.pdf>)

Clinical Criteria

An illness with onset of acute focal limb weakness AND

- a magnetic resonance image (MRI) showing spinal cord lesion largely restricted to gray matter and spanning one or more spinal segments, OR
- cerebrospinal fluid (CSF) with pleocytosis (white blood cell count >5 cells/mm³)

Case Classification***Confirmed:***

- An illness with onset of acute focal limb weakness AND
- MRI showing spinal cord lesion largely restricted to gray matter and spanning one or more spinal segments

Probable:

- An illness with onset of acute focal limb weakness AND
- CSF showing pleocytosis (white blood cell count >5 cells/mm³).