



September 4, 2018

Dear Provider:

Acute flaccid myelitis (AFM) is an illness characterized by acute onset of flaccid limb weakness and magnetic resonance imaging (MRI) showing lesions in the gray matter of the spinal cord. AFM has been under investigation by health departments and the Centers for Disease Control and Prevention (CDC) for the past 4 years. Surveillance has shown us that AFM cases generally peak in the months of September and October. A biennial pattern has been observed, with most cases reported in 2014 and 2016, and smaller numbers reported in 2015 and 2017. If this pattern continues, we should expect to see an increase in AFM cases in 2018. We are sending this letter to encourage you to be aware of the symptoms of AFM and to provide some resources to help with the identification and reporting of suspected AFM cases and specimen collection.

AFM Symptoms:

- Start with a prodromal respiratory or gastrointestinal illness about 1 week before limb weakness onset
- Pain in the neck or back often directly precedes weakness in one or more limbs
- Cranial nerve findings such as slurred speech, difficulty swallowing, and eyelid or facial droop may occur
- On exam, the weak limb(s) displays poor tone and diminished reflexes
- Cerebrospinal fluid may show a lymphocytic pleocytosis and elevated protein
- MRI findings include lesions in the central, or gray matter, of the spinal cord

Since AFM is a relatively new condition, we need information on all patients to help us better understand the spectrum of illness and all possible causes, risk factors, and outcomes for AFM. We ask you to send all information about patients that meet the clinical criterion for AFM (sudden onset of flaccid limb weakness) to the Southern Nevada Health District, by phone at 702-759-1300, fax (702)-759-1414 or online at <https://www.southernnevadahealthdistrict.org/diseasereports/forms/disease-reporting>. Information should be sent on patients who meet the clinical criterion regardless of any laboratory results or MRI findings. Note there is no age restriction for reporting suspected cases. The case definition includes people of all ages to allow us to collect information on the full spectrum of the condition in both children and adults. For more information about the case definition for AFM, please see <https://www.cdc.gov/acute-flaccid-myelitis/hcp/case-definition.html>.

Please find enclosed in this packet some Frequently Asked Questions (FAQs) about AFM and sample collection and shipping instructions. We also included a clinician “job aid” to walk you through the process of reporting a suspected AFM patient and sample collection, storage, and shipping.

For questions, you may contact the Southern Nevada Health District at 702-759-1300 or email the CDC AFM team at [limbweakness@cdc.gov](mailto:limbweakness@cdc.gov).

To notify us of any patients who you are evaluating for acute onset of flaccid limb weakness, please call 702-759-1300.

Thank you very much.

Sincerely,

A handwritten signature in blue ink that reads 'Joseph P. Iser'.

By: \_\_\_\_\_  
Joseph P. Iser, MD, DrPH, MSc  
Chief Health Officer

## Acute Flaccid Myelitis (AFM)

# Frequently Asked Questions by Clinicians and Health Departments



### Q • *What is a suspected case of AFM?*

**A:** A patient who presents with acute flaccid weakness of one or more limbs. No laboratory or MRI results are needed to alert public health officials about a case, and a diagnosis is not needed. The sooner the suspected case is reported, the likelihood of finding a cause is increased.

### Q • *How do I report (alert the health authorities about) a suspected case of AFM?*

**A:** **Clinicians:** If you believe your patient has symptoms of AFM, such as acute flaccid weakness, contact your state or local health department as soon as possible for instructions on how to report. Urgent questions may also be directed to the CDC Emergency Operations Center (770-488-7100). Non-urgent questions can be emailed to the AFM team at [limbweakness@cdc.gov](mailto:limbweakness@cdc.gov). In addition, please collect biological specimens for testing as soon as possible to increase the possibility of finding a cause. These specimens can be tested at a hospital or state public health laboratory for enteroviruses, West Nile virus, and other infectious etiologies known to be associated with AFM. At the same time, additional aliquots of CSF, serum, stool, and respiratory samples should be sent to CDC for testing for both infectious and non-infectious causes. Additional instructions regarding CDC-specific specimen collection and shipping can be found on our Specimen Collection Instructions webpage at [www.cdc.gov/acute-flaccid-myelitis/hcp/instructions.html](http://www.cdc.gov/acute-flaccid-myelitis/hcp/instructions.html). For more information on how to send information about a suspected AFM case, see CDC's [Job Aid for Clinicians](#).

**Health departments:** If you have received information about a suspected case of AFM, complete the [patient summary form](https://www.cdc.gov/acute-flaccid-myelitis/hcp/data.html) (<https://www.cdc.gov/acute-flaccid-myelitis/hcp/data.html>) in conjunction with the clinician, collect the requested clinical information (i.e., admission and discharge notes, MRI report, MRI images, neurology consult notes, infectious disease consult notes, vaccination record, diagnostic laboratory results, and EMG report if done and available), and contact CDC ([limbweakness@cdc.gov](mailto:limbweakness@cdc.gov)), to coordinate the case classification process.

### Q • *Should I send information about a suspected case of AFM even if his/her clinical specimen was negative for enteroviruses?*

**A:** Yes, we encourage information about all suspected cases of AFM to be sent to the health department regardless of laboratory testing results. Although the outbreak of severe respiratory illness caused by enterovirus D68 (EV-D68) and the national cluster of AFM cases occurred around the same time in 2014, the pathogen or biologic mechanism responsible for AFM has not been identified yet. We request information and biological specimens from ANY patient suspected of having AFM (an illness with onset of acute flaccid limb weakness), regardless of whether they test positive or negative for an enterovirus.



U.S. Department of  
Health and Human Services  
Centers for Disease  
Control and Prevention

For more information, visit:

[www.cdc.gov/acute-flaccid-myelitis](http://www.cdc.gov/acute-flaccid-myelitis)

National Center for Immunization and Respiratory Diseases (NCIRD)  
Division of Viral Diseases

**Q** • *Should I send specimens to CDC even if the hospital laboratory or state public health laboratory can test for enteroviruses?*

**A** • Yes, we request that specimens (i.e., cerebrospinal fluid, serum, stool, and respiratory samples) be sent to CDC for standardized testing and for our expanded testing protocols. Contact your health department to coordinate sending of specimens to CDC for testing. Results from certain tests, such as enterovirus/rhinovirus testing and typing and stool testing, will be shared with specimen submitter and health department upon completion. The health department will then share the results with the clinician. For instructions on how to submit specimens to CDC, see our Specimen Collection Instructions webpage at [www.cdc.gov/acute-flaccid-myelitis/hcp/instructions.html](http://www.cdc.gov/acute-flaccid-myelitis/hcp/instructions.html).

**Q** • *What happens to the patient specimens that I send to CDC, and when should I expect to receive the testing results?*

**A** • All specimens submitted to CDC help us learn more about AFM, including possible causes and how the immune system responds to this condition. Results from these tests should not be used to inform clinical management of your patient because results may not be available in real-time. Results from the respiratory testing for enterovirus/rhinovirus and typing and stool testing for poliovirus will be shared with the specimen submitter and health department as soon as they are completed. The health department will then share the results with the clinician. Results from other specimens (e.g., CSF and serum) will be used for exploratory testing to learn more about immune responses to AFM, and results will not be immediately available. Since CDC testing protocols include several immunoassays that are not approved by the Clinical Laboratory Improvement Amendments (CLIA) nor are intended for clinical diagnosis, CDC will be unable to provide patient-specific results for certain tests that are performed. However, results from exploratory testing of samples from multiple cases which may indicate a possible cause of AFM will be rapidly disseminated.

**Q** • *When should I expect AFM case classification results back from CDC?*

**A** • The process for case classification requires collection of many different pieces of information, including hospital notes and MRI images, which are then reviewed by several experts. Case classification is used for surveillance purposes and should not interfere with the differential or final clinical diagnosis or treatment of the patient. The case classification will be communicated through the state or local health department when the review is complete, generally about 4 weeks after all of the information is received.

**Q** • *Will CDC conduct extended follow-up on cases of AFM after their initial clinical presentation?*

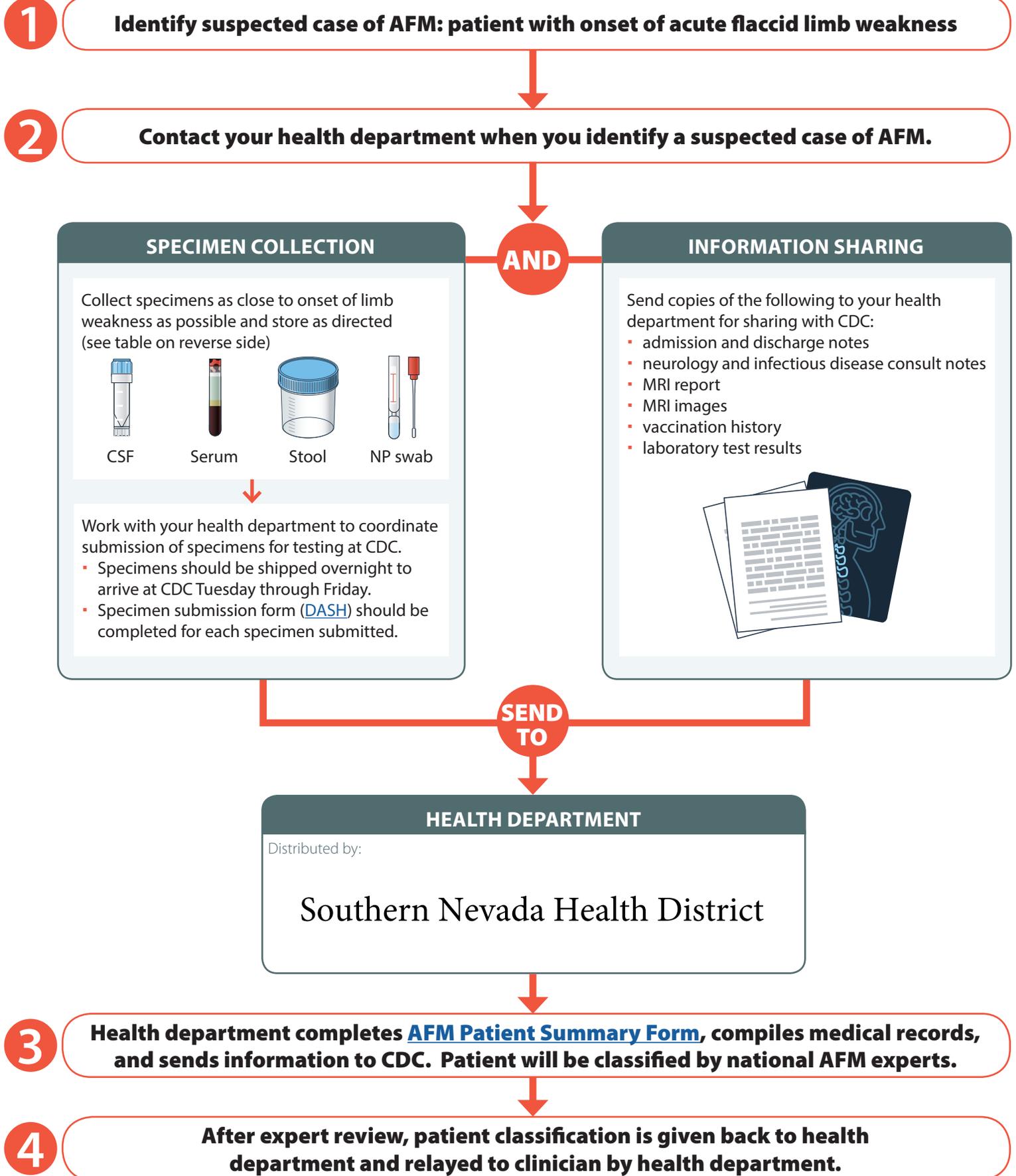
**A** • Currently, we are working with health departments to collect short-term follow-up information (2 months after onset of limb weakness) about suspected cases of AFM. The health department may reach out to the treating clinician to collect this information. We conducted a short-term follow-up survey on cases with information collected during the 2014 investigation, and received responses from roughly half (56) of the identified cases. A small number described complete recovery of limb function after a median of about 4 months after onset of limb weakness. The majority described some improvement of function. A small number described no improvement in limb function. Information on long-term follow-up conducted on AFM cases from Colorado that occurred in 2014 can be found at [www.neurology.org/content/89/2/129](http://www.neurology.org/content/89/2/129).

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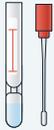
For more information on AFM, visit our For Clinicians and Health Departments webpage at [www.cdc.gov/acute-flaccid-myelitis/hcp/index.html](http://www.cdc.gov/acute-flaccid-myelitis/hcp/index.html).

# Job Aid for Clinicians

How to send information about a suspected AFM case to the health department



### Specimens to collect and send to CDC for testing for suspected AFM cases

SAMPLE	AMOUNT	TUBE TYPE	PROCESSING	STORAGE	SHIPPING
CSF	1mL (collect at same time or within 24hrs of serum)	Cryovial 	Spun and CSF removed to cryovial	Freeze at -20°C	Ship on dry ice
Serum	≥0.4mL (collect at same time or within 24 hours of CSF)	Tiger/red top 	Spun and serum removed to tiger/red top.	Freeze at -20°C	Ship on dry ice
Stool	≥1 gram (2 samples collected 24hrs apart)	Sterile container 	n/a	Freeze at -20°C	Ship on dry ice. Rectal swabs should not be sent in place of stool.
Respiratory (NP)/ Oropharyngeal (OP) swab	1ml (minimum amount)	n/a 	Store in viral transport medium	Freeze at -20°C	Ship on dry ice

**Coordinate with your health department to send information about suspected AFM cases and ship specimens to CDC.**

[www.cdc.gov/acute-flaccid-myelitis](http://www.cdc.gov/acute-flaccid-myelitis)

This job aid was developed by the U.S. Centers for Disease Control and Prevention (CDC).

Distributed by:

**Southern Nevada Health District**