

CDC Case Confirmation for Acute Flaccid Myelitis*

THE TRANSVERSE MYELITIS ASSOCIATION

advocating for those with adem, afm, MOG-ab disease, nmosd, on and tm

ACUTE FLACCID MYELITIS ASSOCIATION

supporting and advocating for those impacted by afm

What is Acute Flaccid Myelitis?

In recent years we've seen an uptick in reports of children and adults being diagnosed with Acute Flaccid Myelitis (AFM). Cases have peaked every 2 years since 2012, and there have been over 500 cases confirmed by the Centers for Disease Control and Prevention (CDC) since 2014. Most individuals diagnosed with AFM are children, although there have also been cases in adults. Symptoms usually include a febrile respiratory illness followed by sudden onset of limb weakness/paralysis and the loss of muscle tone and reflexes. Some individuals have cranial nerve involvement and have a facial droop/weakness, difficulty moving the eyes, drooping eyelids, or difficulty swallowing or slurred speech. Some individuals may also experience respiratory failure where breathing assistance is necessary.

Although a definitive cause for AFM has not yet been established, many experts think it is due to infection from a non-polio enterovirus (EV), such as EV-D68 or EV-71. To better understand the potential causes, optimal treatment, and outcomes of AFM, health departments across the United States are conducting enhanced surveillance for AFM cases.

When children or adults are diagnosed with AFM, cases are reported to CDC, who then publish the data. The process for getting cases to CDC is clunky and, in many cases, parents or patients never hear back if their case was confirmed. The AFM community's long held fear is that cases are underreported to CDC, and as a result, AFM is not getting the attention it deserves. It's critical that CDC has an accurate count of cases so that research for AFM can be properly funded. Better treatment protocols and outcomes should follow research—and it all hinges on CDC having all the information it needs. The details for the case confirmation process are as follows:

How do cases get reported to CDC?

Be a voice! Please urge your clinician to report you or your child's AFM diagnosis to the local health department. Below you can find the steps for cases to be reported to CDC.

1. Clinicians submit the Patient Summary Form, Medical Records and MRI to State/Local Health Departments.

2. State Health Departments pass this information along to CDC.
3. CDC evaluates the case (confirmed, probable) and updates the State Health Department.
4. The State Health Department updates the clinician.
5. The clinician updates the parent or patient.

How do I find out if my case was confirmed by CDC?

If you have not heard back about your case, these are the steps you can take to make sure it was reported.

1. Call your state health department. Find the contact for Infectious Disease or Epidemiology (if that fails, find the press person!)
2. Say, "My child/I was/were diagnosed with AFM in (Month/Year) in (County) and I would like to know my case's status (confirmed, probable, pending) with CDC."
 - If they say your case was confirmed, ask if it was reported back to the clinician.
 - If it wasn't confirmed, determine where the breakdown occurred. Did they get the information from the clinician? Was it passed along to CDC? Are they waiting to hear back from CDC?
 - If the clinician never submitted information, contact your clinician.
 - If the State Health Department sent the information to CDC and are still waiting to hear back from CDC, it is likely the case has not yet been classified. CDC alerts health departments as soon as cases are classified. However, if the health department is unsure of the status, they can contact CDC with the patient's case ID number for an update.
3. If all else fails, email AFMquestions@CDC.gov and they can try to contact State Health Departments. Please be sure to let them know which county/state you live in. CDC will still not be able to verify if your or your child's case was confirmed because their data are anonymous, but they can help connect you with someone at the state department who will follow up with you and provide you that information. **But call your state first —that helps raise awareness of AFM!**

For your Clinician: AFM Classification Information

- An illness with acute limb weakness and:
 - **Confirmed:** A magnetic resonance image (MRI) showing spinal cord lesion largely restricted to gray matter** and spanning one or more spinal segments.
 - **Probable:** Cerebrospinal fluid (CSF) showing pleocytosis (white blood cell count >5 cells/mm³, may adjust for presence of red blood cells by subtracting 1 white blood cell for every 500 red blood cells present).

** Normal or negative MRI images within the first 72 hours of symptoms does NOT rule out AFM. Terms used 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. If you are unsure if this criterion is met, consider consulting the neurologist or radiologist directly.

Specimen Collection and Submittal

Urge clinicians to collect specimens on suspect cases as early as possible, preferably on the day of onset of limb weakness/paralysis, to increase the chance of virus detection.

The following is a check list of specimens and tests the clinician should submit to the health department.

1. MRI (performed within 72 hours) ✓
2. Nose and mouth swabs for viral detection ✓
3. Antibody levels (serum) collected prior to any treatments ✓
4. Lumbar Puncture ✓
5. Stool and urine samples ✓

Additional Resources

The Transverse Myelitis Association
www.myelitis.org

Acute Flaccid Myelitis Association
www.afmanow.org

Centers for Disease Control and Prevention
<https://www.cdc.gov/acute-flaccid-myelitis>

* Some sections were adapted from the California Department of Public Health – November 2018 Acute Flaccid Myelitis (AFM) Quicksheet: ow.ly/GnpX30nHhh1