

Acute Flaccid Myelitis (AFM)

Resources for Families and Clinicians

A compilation of the most frequently used resources about acute flaccid myelitis (AFM) from across the AFM community.

What is Acute Flaccid Myelitis (AFM)?

Top resources for families	URL
For Parents: Helping Children Who have AFM	srna.ngo/cdc/for-parents
What is AFM?	srna.ngo/what-is-afm
Acute Flaccid Myelitis Resources for Families	srna.ngo/aap/afm-resources
AFM Parent Sessions	srna.ngo/cdc/parent-sessions

Top resources for clinicians	URL
AFM Information for Clinicians and Health Departments	srna.ngo/cdc/clinicians
What is AFM?	srna.ngo/what-is-afm
Acute Flaccid Myelitis Working Group	srna.ngo/afmwg
Patient Care: Acute Flaccid Myelitis	srna.ngo/aap/afm

Up-to-Date Cases of AFM in the United States and what CDC is Doing

Top resources for clinicians	URL
AFM Cases and Outbreaks	srna.ngo/cdc/cases
What CDC is Doing	srna.ngo/cdc/what-we-do
Acute Flaccid Myelitis Task Force	srna.ngo/cdc/task-force



Centers for Disease
Control and Prevention
National Center for Immunization
and Respiratory Diseases



Siegel
Rare Neuroimmune
Association

Reporting Suspected Cases of AFM to CDC

Reporting of a possible case of AFM, including specimen collection and testing, is coordinated between the state and local health departments and the treating clinician during the acute phase or initial hospitalization. CDC does not provide a diagnosis or treatment guidelines for individual patients, and the treating clinician should not wait for CDC's case classification to diagnose AFM and provide appropriate treatment. CDC case classification is used for surveillance purposes.

Reporting resources for clinicians	URL
Job Aid for Clinicians Reporting Patients Under Investigation for AFM	srna.ngo/cdc/job-aid
Directory for State & Local AFM Contacts for Clinicians	srna.ngo/cdc/afm-state-contacts
AFM Case Definitions (for surveillance purposes)	srna.ngo/cdc/case-definitions
Data Collection for AFM	srna.ngo/cdc/data-collection
AFM Specimen Collection	srna.ngo/cdc/specimens
AFM Frequently Asked Questions from Clinicians and Health Departments	srna.ngo/cdc/faqs

Reporting resources for parents	URL
Clinicians diagnose AFM. CDC classifies AFM.	srna.ngo/cdc/classify-afm

- › Please note that CDC only receives de-identified information for case reports and cannot identify a child by their name or other personal identifying details. In your email, indicate when and where the child was diagnosed. CDC can help connect you with the appropriate health department, but they cannot directly confirm any details about case classification. If you are unable to reach the clinician, health department, or are uncertain as to whether your child's case was reported, you may email AFMQuestions@cdc.gov.

Learning more about AFM

AFM education resources	URL
AFM Information for Clinicians and Health Departments	srna.ngo/cdc/clinicians
What Pediatricians Should Know about AFM, Free CME Course and Support Material	srna.ngo/aap/cme
AFMWG Educational Resources	srna.ngo/afmwg/ed
AFM Resource Library	srna.ngo/afm-rl



Accessing Medical Professionals after an AFM Diagnosis and AFM Expert Consult

Additional providers or specialists may become an integral part of a child's care team after an AFM diagnosis, including physical or occupational therapists, orthotists, orthopedic surgeons, neuropsychologists, and more. Specialists experienced in treating children with AFM can be located via **Siegel Rare Neuroimmune Association's (SRNA) Medical Professional Network** at [srna.ngo/mp-network](https://www.srna.ngo/mp-network). If you do not see a medical professional or specialist near you or a particular specialty, please email info@wearesrna.org for additional possibilities.

Clinicians with questions about a possible AFM diagnosis or subsequent care may also reach other providers or SRNA staff to connect with an AFM expert through the **AFM Physician Consult and Support Portal** at [srna.ngo/consult](https://www.srna.ngo/consult) or via email at info@wearesrna.org.

Family and Peer Support Opportunities

Resources	URL
SRNA Support Group Network Volunteer-led support groups for anyone diagnosed with a rare neuroimmune disorder	srna.ngo/afm-support
SRNA Peer Connect Program Trained community volunteer one-to-one connection opportunities for those 18 and older	srna.ngo/afm-connect
SRNA Family Camp Annual summer camp for children diagnosed with AFM and their families	srna.ngo/afm-camp
Acute Flaccid Myelitis Association (AFMA) Financial Support Grant Need-based grants available for costs directly related to an AFM diagnosis	srna.ngo/afma-grant
No Time for the Moon Children's Book A children's book and parent/guardian resource for those affected by AFM	srna.ngo/afm-book
Podcasts for Parents A special AFM edition of SRNA's "Ask The Expert" podcast series in collaboration with CDC	srna.ngo/afm-podcasts



AFM Personal Experiences

Listen, read, watch, and learn of the diverse experience of others who've received an AFM diagnosis, and know that your child, and your family, are not alone.

Resources	URL
AFM Stories	srna.ngo/cdc/stories
This is AFM Me	srna.ngo/afm-stories
SRNA Hope Ambassadors	srna.ngo/afm-ha

AFM Research

Opportunities to participate in research studies exist for newly diagnosed, as well as those with an existing diagnosis, and require provider facilitation.

Opportunities	URL
The AFM Biorepository	srna.ngo/cdc/research
The NIH AFM Natural History Study	srna.ngo/cdc/nih-research
AFM Research	srna.ngo/research-studies
Clinicaltrials.gov	srna.ngo/trials

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