

AFM Parent Session Transcript
June 25, 2020

0:03

ANNA: Good afternoon, and welcome to our very first parent session. We're going to wait just a couple of minutes to let a few more people join, and then we'll get started.

1:32

ANNA: Good afternoon, everyone, and welcome to the Centers for Disease Control and Prevention's parent session on an Acute Flaccid Myelitis: What We're Learning.

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ANNA: This is the first session of series that will continue throughout the end of the year.

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ANNA: Today, we have Janell Routh Medical Officer and Lead of the AFM and Domestic Polio Virus Team. Today's conversation will provide you with an update on CDC's investigation of AFM and share what we're doing to learn more.

2:04

ANNA: Dr. Routh will also share guidance for helping your family through recovery, and managing the condition, and touch on AFM in light of the recent COVID-19 Pandemic.

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ANNA: Before we get started, we wanted to flag a few housekeeping items. All participants will be kept on mute to reduce background noise. As such, please share any questions you might have in the questions box on the right side of your screen.

2:31

ANNA: The final portion of our session today will be dedicated to answering questions. Selected questions will be read aloud for the presenter to answer.

2:40

ANNA: If you have any issues in connecting to the presentation, it may be due to a slow Internet connection. Please close all of your other open applications to minimize issues and maximize available bandwidth. If you are having problems with the audio or experienced an echo, it may be due to duplicate open sessions. Please close all of your windows and reconnect to the session.

3:06

ANNA: If you continue to experience these or any other issues, please e-mail us at AFMwebinar@porternovelli.com, which was in your confirmation e-mail, or via the questions box on the right.

3:20

ANNA: This session will be recorded and available online on CDC's AFM website.

3:26

ANNA: So, thank you for your patience and at this time I would like to introduce you to today's presenter, Dr. Janell Routh.

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Dr. Routh: Anna, thank you so much.

3:37

AFM Parent Session Transcript
June 25, 2020

Dr. Routh: Good afternoon everyone. We really appreciate you joining today. I'm going to try to keep my remarks as brief as possible so we can allow as much time for questions and make sure that we can get to as many as are asked.

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Dr. Routh: I want to especially thank the Siegel Rare Neuro Immune Association and Porter Novelli for setting up this question and answer session. And we certainly look forward to speaking with you today about CDC's work on AFM.

4:03

Dr. Routh: As Anna mentioned, my name is Janell Ruth.

4:06

Dr. Routh: I'm a pediatrician in the Division of Viral Diseases at CDC, and the Team Lead for AFM. I wanted to say a couple words about the team. It's composed of physicians and epidemiologists, as well as partners in the CDC Laboratory, and Communications. We all work together on the activities that I'll highlight today. We are a very dedicated group, and I just wanted to let you know, we have all deliberately chosen to work on AFM because we do feel this real commitment to answering questions about this emerging illness. I'm joined today by my Division Director, Dr. Steve Oberste, and our Deputy Division Director, Dr. Thomas Clark, and they'll both be joining me in the question and answer session.

4:47

Dr. Routh: Next.

4:51

Dr. Routh: So I joined AFM team in 2016, and when I look back over the last four years, I'm most excited by the growing community of clinicians, public health practitioners, laboratorians, and researchers who have all come together to collaborate and share information about AFM.

5:08

Dr. Routh: Shown here on the slide, is just a small slice of the community put together with CDC, looking for answers to the questions that remain about AFM. I know many of these faces must look familiar to you, and you've probably received excellent support and care for both you and your family.

5:26

Dr. Routh: We each play a unique role from direct clinical care to public health surveillance to basic research on AFM pathogenesis and prevention. No one individual can provide all of the answers to the questions that remain about AFM, and it's why I feel particularly fortunate to be joined by this larger community.

5:46

Dr. Routh: Next.

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Dr. Routh: Most importantly, I feel grateful to be part of the AFM community of patients and their families.

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Dr. Routh: In early 2019, 1 of my best memories was meeting parents of children with AFM when they came to address the AFM Task Force at CDC. Their stories gave us the opportunity to

AFM Parent Session Transcript
June 25, 2020

understand this illness through the eyes of families who had been directly affected by AFM and speaking for myself. It was a powerful reminder of why we do the work that we do.

6:18

Dr. Routh: Later in 2019, I was invited to the SRNA Symposium in Columbus, Ohio and was able to meet other parents and sit and talk with them about, how AFM affects their day-to-day life.

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Dr. Routh: I was really grateful that they chose to share those small details of daily life that make this illness so challenging to live with.

6:39

Dr. Routh: I was also really excited to hear the successes and improvements that their children have made over time. And I came back from that conference, really, with a renewed conviction about how we can all work together and what we can accomplish. And it's why I'm really happy to be here today to strengthen that communication bridge that we have with each other. We're always here to answer your questions: So, even if you don't ask one today, but you think of something later on, please know that we are here for you to answer those questions. We have a dedicated parent box where you can send those questions that's constantly monitored, and I'll put that e-mail address up at the end of the slides.

7:22

Dr. Routh: Next.

7:26

Dr. Routh: So this slide shows a timeline of AFM outbreaks since CDC began tracking AFM in 2014, and our activities since that time. Just a small slice of our activities. And we can certainly talk more about those during the question and answer session.

7:40

Dr. Routh: AFM was recognized in 2014, after a cluster of nine cases in Colorado, and we immediately issued a call for additional cases nationwide. In 2014, 120 cases across the US were confirmed as AFM.

7:55

Dr. Routh: In 2015, CDC started a national surveillance system and created a standardized case definition for the illness, and we'll talk more about that case definition shortly. 2015 saw 22 cases confirmed across the country, and then in 2016 we saw that second outbreak of AFM occurring, and with that 153 confirmed cases.

8:17

Dr. Routh: This is the year that I joined the AFM team.

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Dr. Routh: In 2017, we confirmed 38 cases, and in 2018 we had our third and largest outbreak, with 238 cases confirmed. In 2018, we also established our AFM Task Force, which is a national collaboration between CDC and national experts in Virology, Immunology, Neurology, and Infectious Diseases, who all come together to set the AFM research priorities.

8:46

AFM Parent Session Transcript
June 25, 2020

Dr. Routh: In 2019, we saw 46 confirmed cases, which is pretty typical for what we see in a non-outbreak year.

8:54

Dr. Routh: In 2019 our lab collaborated with other centers on AFM biomarkers and diagnostic testing, and published the results of enterovirus antibodies in the spinal fluid of AFM patients, which I think was a very interesting finding. One of the more important newer findings that has been uncovered about AFM.

9:08

Dr. Routh: This year in 2020. If our prior surveillance holds true, we should see another increase in cases this late summer or early fall, and we're certainly busy tracking reports of cases to CDC every day, and I'll talk more about our preparations for 2020 in just a minute. But to let you know, we haven't seen an increase in case reports, which is pretty typical for this time of year. Next.

9:42

Dr. Routh: So, here's a very brief summary of what we've learned from six years of surveillance.

9:48

Dr. Routh: We've thoroughly investigated every reported case of AFM, and it's important to emphasize that we learn from every case, regardless of whether they're actually confirmed.

9:59

Dr. Routh: Through national surveillance, our partnerships with the AFM Taskforce, and the working group, SRNA and others. We know that most cases have been in children greater than 90% of our AFM confirmed cases, are in children.

10:14

Dr. Routh: The most common signs and symptoms are arm or leg weakness with loss of muscle tone and reflexes.

10:21

Dr. Routh: That most patients, certainly an outbreak years develop AFM between August and November. And most patients have respiratory symptoms or a fever prior to limb weakness onset.

10:32

Dr. Routh: No AFM cases have been caused by poliovirus, we test every stool sample that is sent to CDC for polio, and have not found it to date.

10:42

Dr. Routh: But we do believe that non polio enteroviruses are likely the cause of those biennial outbreaks that I just mentioned.

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Dr. Routh: Currently, there is no proven treatment or prevention strategy for AFM and this last point, I think, is the most critical.

10:58

Dr. Routh: We still have a lot more to uncover and many questions to answer about AFM so that we can determine the best treatment and prevention strategies.

AFM Parent Session Transcript
June 25, 2020

11:06

Dr. Routh: Next.

11:10

Dr. Routh: So we don't know what will happen this year. Social distancing measures and hygiene recommendations for coronavirus may have a positive impact on the AFM and specifically, those measures may impact the circulation of viruses, including enteroviruses that we believe trigger AFM.

11:29

Dr. Routh: This could delay, or even eliminate that peak in cases that we generally see an even numbered years, and I am trying to think of that as a silver lining to this pandemic.

11:40

Dr. Routh: Regardless, we are prepared for an outbreak if it should occur in the late summer or early fall of this year, and we're preparing in the following ways.

11:48

Dr. Routh: One is that we've developed an internal emergency response activation plan. Once the outbreak begins, our team will launch into that incident command structure we call it. Secondly, we're raising awareness among healthcare providers and parents so that they will think AFM if they see symptoms consistent with this illness.

12:09

Dr. Routh: We're helping health departments prepare for an increase in case reports, even despite the fact that they're busy responding to COVID-19, we've been updating our AFM materials, including some new web pages on the website.

12:24

Dr. Routh: We're working with partners to make sure we learn as much as possible about AFM this year, if indeed it does return.

12:32

Dr. Routh: I think I've said this before, AFM is not like other illnesses for outbreaks or influenza or measles.

12:40

Dr. Routh: We have tools in our toolbox, like treatment, prophylaxis, we isolate cases, or we quarantine exposed patients, or even vaccination is used sometimes to slow or stop an outbreak.

12:56

Dr. Routh: But for AFM right now, the biggest component in our toolbox is awareness, making sure that a clinician recognizes acute flaccid weakness as a potential emergency and act promptly to get that patient to medical care, is the primary focus of our response. We want to make sure this year, that not one single child with limb weakness is missed as a possible case of AFM.

13:19

Dr. Routh: Next.

13:23

Dr. Routh: So, as we prepare for this year's anticipated outbreak, and tracking of AFM cases through national surveillance, I did want to take this time to help to clarify. Again, the differences between diagnosis of AFM and case classification.

AFM Parent Session Transcript
June 25, 2020

13:38

Dr. Routh: I know this question comes up a lot, and many have asked about it. So I thought I'd address it upfront.

13:45

Dr. Routh: Public health surveillance for AFM serves a different purpose than making a diagnosis of AFM. And I want to emphasize I'll probably emphasize the several times throughout our discussion, that the CDC case classification of a suspected AFM case should never replace or take precedence over that clinical diagnosis.

14:05

Dr. Routh: A diagnosis is based on full information.

14:09

Dr. Routh: The patient's history of illness, a physical examination, and multiple diagnostic tests that are used ultimately to make that one diagnosis.

14:19

Dr. Routh: It aims to be as accurate as possible, to provide the best care and treatment for that individual patient. And it usually happens during hospitalization. So within the first few days of hospitalization, doctors have some idea of what might be causing those symptoms.

14:35

Dr. Routh: Public health surveillance and case classification, on the other hand, is done through review of some of the patient's medical records, and most importantly, their MRI images.

14:46

Dr. Routh: Standardization, using case definitions helps us to measure the disease burdens and trends across time, so that we can compare from year to year.

14:56

Dr. Routh: Classification may be delayed. It takes time for a clinician to report to the health department, and it takes time for the health department to report to CDC. We are working to make that time as short as possible.

15:09

Dr. Routh: But, once we get the information on every case, our neurology panel does review the images and the information and return a classification, and that just takes a little bit longer than diagnosis should.

15:24

Dr. Routh: Finally, you know, we really do try to balance wanting to cast a wide net.

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Dr. Routh: So, capture every AFM case that we possibly can, that that's happening in the United States. But also, we want our cases to fit into a certain mold or cookie cutter fits that case definition, so that we can compare them from year to year. So, we're always striking a balance with surveillance.

15:53

Dr. Routh: Maybe to emphasize, one more time, that case classification should not take precedence or replace a clinical diagnosis of AFM. And we do want to emphasize both to parents, and to our treating physicians, that we want patients to be hospitalized and get referred

AFM Parent Session Transcript
June 25, 2020

to specialists. Be monitored for signs and symptoms of worsening illness, and certainly begin treatment and rehabilitation plans as soon as possible.

16:22

Dr. Routh: Next.

16:26

Dr. Routh: So, with that very brief introduction, hopefully, we will talk a lot more about what CDC is doing, and answer questions during the Q&A portion of this listening session. Right now, what I'd like to do is turn it over to a wonderful colleague, Rebecca Whitney, from the Siegel Rare Neuro Immune Association, to, say, a few words. Rebecca and her colleagues from SRNA have collaborated with us on ways to support outreach and awareness about AFM and have been one of that main connections between patients and families. So, we're incredibly grateful for their strong partnership and for making this session possible today. So, with that, Rebecca.

17:08

Rebecca: Thank you so much for your kind words, and for hosting this session, Dr. Routh for CDC, for providing the opportunity for families to connect with you via the session today and for including SRNA. So, and thank you family so much for attending today. My name is Rebecca Whitney in the Pediatric Programs Manager for the Siegel Rare Neuro Immune Association, SRNA is a non-profit dedicated to the support of children, adolescents, and adults on the spectrum of rare neuro immune disorders, specifically including Acute Flaccid Myelitis. We actually began in 1994 as the Transverse Myelitis Association.

17:50

Rebecca: And I've been advocating for the research education and support of those diagnosed with AFM since that time. Until 2014, those with inflammation in their spinal cord, and the persistent loss of limb, weakness or paralysis were still being diagnosed as transverse myelitis. AFM is now obviously referred to as a separate disorder, but there's still so much overlap in these particular rare disorders with regard to their presentations, treatment, and recovery. Many families listening may have even received an initial diagnosis of TM or ADEM acute disseminated encephalomyelitis or may have heard of MOG antibody diseases and conversations with their neurologists. All of these disorders can be very difficult to differentiate and diagnose.

18:35

Rebecca: It can also be incredibly difficult to capture the interests of researchers and be certain that medical professionals are educated about this disorders.

18:43

Rebecca: We believe as a rare disorder community with subsets that are even more rare or stronger together.

18:50

Rebecca: Some of you may already be familiar with our names, our organization, or some of our programs, such as our Quality of Life Family Camp, Symposia, or podcasts. You may have even talked with their e-mail with me or one of my colleagues.

19:03

Rebecca: As individuals diagnosed and parents and caregivers of loved ones also diagnosed with these rare disorders, it's our passion and our commitment to our app and families to connect with

AFM Parent Session Transcript
June 25, 2020

you, support you an advocate for you via research, education, and community awareness opportunities.

19:22

Rebecca: If you do have any questions of or about our organization, we welcome them all, And I hope you found this session, and the information provided so far, helpful. And I'm looking forward to hearing all of your question.

19:38

Rebecca: Thank you.

19:40

Thanks, Rebecca.

19:52

ANNA: OK, so now we're going to walk through some of the questions that we received ahead of time, and then we'll go through any questions that we get in the box. So my first question to you, Dr. Routh, what acute treatments should I be asking for for my child?

20:13

Yes, great question, and I think one that is on the forefront of every parent's mind when their child is suspected or diagnosed with AFM.

20:24

Right now, there are no current, proven treatments for AFM.

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I know that, our clinical community across the United States does give varying treatments for AFM, including IVIG, immunoglobulin, steroids are used, plasmapheresis, which is sort of an antibody exchange.

20:52

All of those have been used, but there is no proven evidence that that they are effective in AFM as of yet, and I think that is an area that we need to strengthen in terms of our research, one thing that I'm really excited about this year is the NIH Natural History Study for AFM. So, this is a prospective study for patients with acute suspected AFM. They will be enrolled in this protocol that's taking place in about 30 to 35 centers across the United States. And this will be the first time we will be able to systematically follow patients, care treatments, and outcomes over time. I think this is really going to give us a better sense of the information that we need to support one treatment versus another.

21:42

I think, as all of you know, and can imagine, with a disease that isn't particularly common, it can be difficult to compare when there are multiple different hospitals around the country. And so, this is an effort to bring data collection from all of those different hospitals together. So, we're definitely looking forward, you know, again, our hope is that we don't see AFM this year, but if we do, we're hoping that we will enroll in that protocol and start to learn some information about treatments.

22:17

ANNA: Great. Thank you. Our next question, will my child recover from this? How long can I expect recovery to take?

AFM Parent Session Transcript
June 25, 2020

22:27

Dr. Routh: So, another great question, and I think something that is in the forefront of parents minds, as well.

22:35

Dr. Routh: We are currently learning more about recovery, I think in the information that we currently have, there's a spectrum of recovery from locations that do seem to recover fully and quickly to others that have long term paralysis and special needs associated with their AFM disease. I think we would like to learn more about that, and one thing that CDC is doing is to start systematically looking at our long-term outcomes across all of our AFM patients. I think, maybe even some parents on the phone, watching this webinar today, have been contacted by a health departments, who are asking a series of standardized questions about recovery. And it's our hope that we'll be able to collect this data on AFM, both confirmed and probable cases, to better understand what long-term outcomes look like.

23:30

Dr. Routh: We have started that process with our 2018 cases and we will be doing that moving forward, but we also have contracted with another organization to go back to 2014 and contact patients and their families to find out about recovery as far back as 2014. One thing I can say is that, in speaking with parents, one thing that's been very hopeful to me is that it sounds like recovery, there doesn't seem to be a plateau, as with some other neuroimmune diseases. That recovery continues year after year, and, and they do really continue to see progress with their children. So, I think that emphasizes the importance of continuing with ongoing physical and occupational rehabilitation programs to make the most of that recovery process.

24:27

ANNA: Thank you. The next question. What does CDC think AFM will look like this year in light of the COVID-19 pandemic?

24:37

Yes. It's the question on all of our minds. I think, so, I say, our team has been quite protected from the CDC's COVID response because we are working so hard to raise awareness amongst providers across the country. We have mounted a huge outreach and awareness campaign, and our whole team has been involved with that. I might direct that question to my Division Director, Dr. Steve Oberste, who has been very involved in the COVID-19 response, and he may be able to shed a little bit of light on that very intriguing question.

25:12

Dr. Oberste: Yeah, thank you, Dr. Routh, as you said, we don't really know what to expect in 2020 for AFM or whether the COVID-19 outbreak or pandemic will change that pattern that we've seen. However, we are prepared to respond, if we do see the pattern that we've seen in the last few years. AFM remains a high priority for CDC, as it always has been since 2014, we take these outbreaks very seriously.

25:43

Dr. Oberste: Through the AFM Taskforce, We've built robust collaborations with a number of experts across the country to focus on the research agenda and to try to learn as much as we can about this illness, to both improve treatment options, as well as one day to develop preventive measures, which is our ultimate goal.

26:04

Dr. Routh: Thanks, Steve.

26:07

ANNA: OK, the next question: Given the clinical similarities between polio in AFM and the similar causal link, isn't AFM a modern-day polio?

26:21

Dr. Routh: So, yes, the two illnesses do resemble each other but I will say, again, as we've learned through our surveillance data there are some striking differences.

26:35

Dr. Routh: I just lost my train of thought. But yes. So I think one thing to say is that both of these illnesses are representative of a class of illness called acute flaccid paralysis. Both manifest as a flaccid limb weakness. And we do know that both AFM and poliomyelitis have those distinctive gray matter lesions in the spinal cord.

27:00

Dr. Routh: But interestingly, to note that most of our AFM cases or the majority, actually have upper extremity paralysis. So when we look at the number of limbs affected and where those limbs are affected in our AFM patients, we note that I think about 47% have upper limbs only affected. And about 16% have lower limbs only affected, which is almost the reverse of what we have seen in historic poliomyelitis cases where it's more often the lower extremity. One thing is does this give us a clue about pathogenesis? How these non-polio enteroviruses and in particular EV-D68, that we think may be causing those every other year peaks in cases. Does it give us a clue as to how it is getting into the nervous system. We know that EV-D68 is a respiratory virus unlike polio virus which replicates better in the gut or gastrointestinal tract.

28:06

Dr. Routh: And so we're wondering if that respiratory predilection for EV-D68 more directly communicates to the upper spine, as opposed to polio, which replicates in the in the lower the GI tract, may have a more direct route into the lower spine causing that lower extremity paralysis. So, so, yes, I think there are some similarities for certainly between poliomyelitis and AFM. In fact, the terminology is, is even a little artificial, but we are seeing distinct differences between the two illnesses that are important to focus on as we move forward with understanding treatment, and then also ultimately prevention.

28:57

ANNA: Truly fascinating. The next question: Is there testing or studies that affected families can be part of?

29:06

Dr. Routh: Yes, so, one that I just mentioned was the NIH Natural History Study, and that is something, for mostly acute patients only. So they are really taking patients within the first 30 days of limb weakness, and enrolling them prospectively in the Natural History Study. CDC will be doing a similar study, not quite focused so much on the history, but also to try to enroll those patients with suspected AFM and collecting samples for an AFM bio repository. The idea would be to store key specimens from patients in order to help with research efforts in the future.

29:53

Dr. Routh: One study that I do know about that is ongoing and is for patients who have been diagnosed with AFM is out of Johns Hopkins University. It's Priya Dougal's study on genetics. I

AFM Parent Session Transcript
June 25, 2020

think it's a fascinating study. Again, we are very curious about the risk factors for AFM. Just going back to thinking about Enterovirus D68, we know it's a pretty common virus, and it's been around for awhile. So why out of the thousands of infections with this virus, why are there only a small number of children who go on to develop paralysis? What are those risk factors for developing AFM? And so, Priya's study, Dr. Dougal's study, is looking to explore some of the genetics around the AFM.

30:44

Dr. Routh: And so, that would be something that AFM families could get involved with. What we are trying to do at CDC, is create a resources page for families, and so, I hope that we will have either links or information about all of these, in one place.

31:01

Dr. Routh: I am sure that Rebecca and SRNA also have some similar resources on the SRNA homepage that you can go and look for as well.

31:13

ANNA: Great, and Rebecca sent me a message. She said and then CAPTURE is the pediatric study and core TM is long term. And SRNA does have a patient registry as well.

31:26

ANNA: Great, So before I asked my next question, for those who are watching, you can also send us messages in the chat box, either there or questions. We can see them both, so whatever is easier for you. So our next question, If I have a child with AFM, are my other children more susceptible to AFM if they get an enterovirus, when it circulates? What about my child with AFM?

31:52

Dr. Routh: Right, two points that we know. One is that even though we hear stories that like entire families seem to get sick around the time that the child develops AFM. So, you know, we hear that the whole family had a viral illness or cold symptoms. We only see, at least, to my knowledge, that there has been one child affected by AFM in that family, it's never been more than one.

32:25

Dr. Routh: The second thing to note is that again, to our knowledge we have never had a child who has gotten AFM more than once.

32:35

Dr. Routh: So, for example, if, if they had an upper extremity paralysis, we've never had a child that has come back the following year saying they developed AFM again and now it's lower extremity.

32:49

Dr. Routh: So I think those two points are helpful. Again, we're still trying to look for the risk factors that are involved in developing AFM. You know, one thing, as I mentioned, could be genetics.

33:03

Dr. Routh: And so we do have colleagues who are looking into that, I think, you know, there are questions about the virus itself, you know, I think a lot of people have questions about, we know Enteroviruses and EV-D68 have been circulating for a long time. Could it be that the virus has

AFM Parent Session Transcript
June 25, 2020

changed somehow and is now causing more of a neurologic disease than an upper respiratory infection?

33:34

Dr. Routh: Definitely have both at CDC, and other researchers across the country are looking into that neuro variance.. Has the virus changed in some way to have a have a predilection for nervous tissue. I think it is reassuring to note that over our years of surveillance, we have not found a family that has been affected more than once with AFM. We also get asked the question, you know, does AFM occur in clusters? Do we see clusters of children, cities being affected at the same time? We do investigate that. And I can tell you that we have never found a connection between AFM and other what we call like epidemiologic factors that connect those two cases. There was one instance two years ago now, in 2018, where we did have three AFM cases at a daycare facility. That was due to an unusual outbreak of a different enterovirus, enterovirus, A-71, commonly causes hand foot and mouth disease, where you see blisters on the palms and soles of the feet. And during that outbreak in Colorado, we did have three cases, from one day care. But that is the only instance we know of AFM ever clustering in one place.

35:04

Dr. Routh: Normally, cases are scattered throughout the country, and, again, no connection between

ANNA: OK, thank you. I know you've covered a little bit in this in your presentation, but can you talk a little bit more about how CDC determines if a child case is or is not AFM?

35:24

Dr. Routh: I wish it was easier. So I know for many illnesses, again, I go back to influenza or for measles. We have a laboratory test. And so we can take a bit of blood or a cheek swab and we can run a test and say, yes, your child has this disease.

35:40

Dr. Routh: For AFM, we don't yet have that laboratory test, and I am excited by the progress that has been made. Certainly, in 2019, as I mentioned, there was some really novel work that was done. CDC collaborated with University of California, San Francisco and also Columbia University in New York to look at enterovirus antibodies in the CSF.

36:03

Dr. Routh: You know, one thing that is frustrating, I'm going off on a little bit on a tangent, but I'll come back, is that for most of the specimens that we receive at CDC, we don't find an organism. We don't find an etiology. Most of our specimens test negative, including CSF, which is kind of that gold standard sample. If we did find a virus in the CSF, that really would be indicative that that was the cause of AFM, but to date, I think only 2% of our CSF samples have ever tested positive for a virus. So, finding those enterovirus antibodies in the CSF of AFM patients, and the spinal fluid of AFM patients was, I think, a real breakthrough in our understanding of this illness.

36:48

Dr. Routh: So, it would be really nice to have just a very simple and easy laboratory test to differentiate AFM from something else.

AFM Parent Session Transcript
June 25, 2020

36:56

Dr. Routh: We don't have that yet. So how we go about doing that at CDC is to use some pieces of medical information, and most particularly the neurology exam and the MRI to make that classification.

37:10

Dr. Routh: So, we constructed case definitions for AFM and as probably many of you know online, a confirmed case is a case of acute flaccid weakness. So the neurologic exam gives us that information about acute flaccid weakness, and then spinal cord lesions that are predominantly in the gray matter, and it's the MRI, and that give us that information. I am a pediatrician, but I have no neurologic expert, and so we contract with seven now different neurologists across the country who have expertise in AFM to make those determinations. Each cases reviewed by two neurologists independently, if they agree on that case, classification, that is the final case classification. And if they disagree, we send it to a third neurologist for adjudication.

38:02

Dr. Routh: So that is how that classification process works. Once we are given the final case classification, we communicate that back to the health department. And then the health department communicates that back to the clinician and family. I know that process has not worked perfectly, and I'm sure there are lots of nods from people in the audience. We are working very hard to strengthen and close the loop on that process this year. So, I am hoping that there will be better communication between us, the health department, and families, to know that final case classification.

38:41

ANNA: Great, And last question I have thus far, unless we see any more pop up is, why is it so difficult to come to a differential diagnosis in AFM, our physicians have struggled with coming to a conclusion, and I'm afraid it's taking too long, and my child won't recover.

39:01

Dr. Routh: So, I think, as Rebecca mentioned in her remarks, AFM can look remarkably similar to other medical conditions, transverse myelitis, for example, something called Guillain Barre syndrome. Even things like spinal stroke can mimic the both exam findings and MRI findings, we see in AFM. So, I think on initial presentation that can be difficult to say that's AFM versus one of these other conditions. It's why we emphasize that for every patient that comes to medical attention, and hopefully, more patients will come to medical attention now that we're spreading information and increasing awareness about AFM, those patients need expert medical care and consultation with clinical experts.

39:55

Dr. Routh: So infectious disease and pediatric neurologic experts who can really guide the diagnosis and management of the patient. I don't think Rebecca mentioned this, but it's incredibly important and I do want to get the word out about this SRNA in conjunction with neurologic experts around the country, have developed a clinical portal. And this is a place that clinicians can go when they're faced with a patient with acute flaccid limb weakness, to get an expert consultation in how to go about with that diagnosis and management of the patient. They fill out a form online, and then within 24 hours they are called back by one of those medical

AFM Parent Session Transcript
June 25, 2020

experts. So, I do want to highlight that as a really key piece of, of assistance for clinicians across the country, moving into 2020.

40:57

Dr. Routh: So the second part of the question was about, you know, just worried about getting the appropriate treatment and recovery.

41:07

Dr. Routh: I think it's very important to get that diagnosis and it's important to get it right because there are treatable conditions that look like AFM transverse myelitis, for example, does have associated treatments with it. MOG antibody disease, as Rebecca mentioned, has an associated treatment with it. So it is important that those specialists in Neurology and Infectious Disease help to guide that management, because in some cases, there is available treatment. And so as parents, you all can advocate for both your children and others that you may come into contact with on the FSM Facebook page, by highlighting that clinical resource for clinicians across the country.

41:58

ANNA: OK, there are some more questions, so I'm just going to keep going what if my child didn't have a virus or wasn't otherwise ill prior to his AFM diagnosis. Is it still AFM?

42:05

Dr. Routh: Great question, and the answer. The short answer is yes. It can still be AFM.

42:20

Dr. Routh: You know, as I mentioned, for that, for diagnosis, there are just many different pieces of information that need to be considered when thinking about whether to make that diagnosis of AFM. A virus may be a piece of that, but it's certainly not the only piece.

42:38

Dr. Routh: When I mentioned that the in the specimen that come to CDC, it's rare to find the virus in those specimens, and I think one key issue with that specimen collection is timing and probably many parents who are listening right now recognize that their child had symptoms of a that resembled a viral illness prior to limb weakness onset. It may be that that's actually the best time to collect the specimens to determine what, what the etiology, what the bug is.

43:13

Dr. Routh: But most of us don't really either seek medical attention for cold like symptoms or if we go to the pediatrician, the pediatrician doesn't necessarily collect all of the samples that are necessary. So we have to wait until limb weakness onset before we start collecting specimens. And that puts us a little bit behind the eight ball already, which means it's so important to, once limb weakness is recognized to collect the samples as soon as possible afterwards to have the best chance of finding some virus in in any of those specimens. But, but finding the virus is not the golden key to making that AFM diagnosis. It, it comes from a whole host of diagnostic tests, and that MRI to determine what the diagnosis.

44:05

ANNA: Thank you.

44:07

ANNA: I'm just scrolling through to the next question. Has CDC see seen any cases where AFM has occurred this year?

AFM Parent Session Transcript
June 25, 2020

44:16

Dr. Routh: Yes, so good question. We do think that there is a low-level baseline rate of AFM. And that has been probably going on for, for many, many years, decades.

44:30

Dr. Routh: We think something to change in 2014. And so, you know, that low-level baseline that we see was interrupted in 2014 by an outbreak. We went back to that baseline rate in 2015, 2016, again, and brought an outbreak. So something changed in 2014 to give us this unusual pattern and we're still trying to figure out exactly what that was.

44:53

Dr. Routh: But so this year so we see cases low-level number of cases pretty much in most months, but just 1 or 2 cases every month. And so far, in 2020, we've confirmed nine cases we've had, I think, 29 reports of suspected cases to CDC. And of those 29, we've confirmed nine so far. So, again, we're still at that low-level baseline point, wondering what's going to happen August and September.

45:23

ANNA: OK, the next question. What efforts are being made to provide updates from CDC to healthcare providers? Our pediatricians don't have any updates on AFM unless we update them, and we also need to explain. It looks like this parent is doing most of the explaining to the physician.

45:47

Dr. Routh: Thank you.

45:48

Dr. Routh: I think, you know, outreach has all forms, and, know, we certainly are trying our hardest, particularly this year, and I'll tell you a little bit more about those efforts. But, it really does take a village, I think, to get the word out.

46:05

Dr. Routh: It's public health practitioners, it's clinicians talking to clinicians, and it is also parents, talking to their clinicians. I think, if we come together and we all start getting the word out about AFM, it will work a lot better than just one piece or another.

46:24

Dr. Routh: CDC this year has mounted a huge outreach and education campaign, and I can say that because I've given a lot of webinars so far this year to a variety of professional organizations, including AAP. So, the American Academy of Pediatrics has taken a special interest in AFM this year, and we are working with them to get the word out. Our communications team has paid media ads that are now being blanketed throughout many different pediatric journals and newsletters that pediatricians tend to read. So I think that is going to be something new this year that will really catch their eye and make them take note.

47:07

Dr. Routh: CDC is doing a couple big outreach efforts, that are, that are about to come, actually, three, I can think of one on July 8th. We're going to be doing a CDC webinar for all clinicians that want to attend. This will be giving them clinical information about AFM talking through some of the epidemiology and what we're doing in terms of reporting.

47:30

AFM Parent Session Transcript
June 25, 2020

Dr. Routh: Because, again, I feel like one point is to make clinicians are aware of the symptoms of AFM the other pieces to get them to report cases to their health departments, so that we can learn more about AFM. So, we've got the webinar coming up, the eighth of July, I'll be doing a Public Health Grand Rounds with some other colleagues and Rachel Scott from the group. So, that is going to be broadcast on July 21st, and that also tends to attract a wide clinical audience.

48:03

Dr. Routh: And then we have a CDC vital signs release. Vital signs, is something where CDC, every month takes an emerging issue and, and builds lots of infographics, information and a big media campaign around that release. And so on August 4th, we're going to be releasing a manuscript that talks about our 2018 surveillance data, what we learned from those 2018 confirmed cases, as well as doing a telebriefing on, on that release. So I'm hoping that will also generate a lot of media attention just before that expected outbreak.

48:46

Dr. Routh: So, yes, lots of things are going on. You know, Rebecca and RNA have been really fantastic there designating the month of July as AFM Awareness Month. We're going to be doing a whole slew of podcasts that month, to try to get the word out, as well.

49:02

Dr. Routh: And so, yes.

49:05

Dr. Routh: Just, you know, this, the summer has been really incredible that, despite the COVID response and people's attention being drawn away, we are really hammering home this message that AFM is around the corner, and we all need to be prepared.

49:22

ANNA: Great. Thank you, and just as a reminder to those joining us today, we have information on many of the things that you just mentioned Janell on the AFM website on CDC's webpage. So, I'll mention this again in a minute, but this is where you will find the recording of today's session. There's information on the upcoming July Clinician webinar. So definitely look there, and that's, of course, also where we will have Vital Signs posted when that comes out. So, the next question for you is, what are the impacts of COVID-19 on AFM children? I know you covered that a little bit, but we've gotten the question since your earlier comment.

50:03

Dr. Routh: No, I think it's a good point.

50:04

Dr. Routh: I think, if I'm understanding the question correctly, are perhaps AFM children, children with AFM more at risk, for COVID-19? I think that that might be the question. There was some good discussion about that, I think, and the Johns Hopkins Symposium that Carlos Pardo and the AFM workgroup have put on.

50:28

Dr. Routh: It's difficult to know if, if children with AFM are at increased risk, just inherently for COVID-19 infection? You know, I think, certainly, we all know AFM children who are on ventilators and I think certainly they are at higher risk for infection and higher risk for severe infection just because of those respiratory difficulties. So those would be the children I would be most concerned about.

AFM Parent Session Transcript
June 25, 2020

51:01

Dr. Routh: Does a child who had AFM and has recovered a lot of function? Are they at increased risk for COVID infection? I don't think we know the answer to that question yet.

51:13

Dr. Routh: Yes. I mean, you know, just in general, it seems like children are less affected by COVID-19. Although, we all know and we're starting to hear reports of this multi system inflammatory syndrome that is affecting children. I don't think that we, in the sense that is more common in children with AFM, but certainly we are trying to learn as much as we can, about covert about that multi system inflammatory syndrome, and certainly how it interacts with that with our patient community.

51:48

ANNA: Wonderful. Well, we have a handful of questions that we were not able to get to today, but we will be sure to reach out back to everyone that sent a question and respond. So, please know that if we didn't get to your question today, we will make sure to connect with you. Again, as I mentioned, following today, we will be posting the presentation, a PDF of that, on the AFM website. We'll also post a recording of today's session and a transcript.

52:18

ANNA: So just wanted to say thank you, Dr. Routh, thank you to Rebecca. And thank you to everyone who joined. This is our first of several sessions, so also thank you for the grace as we worked through our first GoToMeeting parents session. It is always a challenge. Of course, I had to make the mute issues but better than anyone else. So again, thank you to everyone for joining, and thank you for your time today. And we look forward to the next one, which we will be sure to share through SRNA and the other ways that this was promoted. So, again, thank you, Dr. Routh, thank you, Rebecca. Hope everyone has a wonderful rest of your day.

52:59

Dr. Routh: Thank you so much for moderating, we really appreciate it. You're welcome. Have a good day, Everyone, bye, bye.