AFM Parent Session Transcript
November 12, 2020

ANNA OKULA: Well hello, everyone, and welcome to the Centers for Disease Control and Prevention's Parent Session, an update from CDC on AFM in 2020.

This is the second parent session in the series. 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 are doing to learn more. Doctor Routh will also share guidance for helping your family through recovery, and managing the condition, and touch on AFM in light of the ongoing COVID-19 pandemic.

We also have Rebecca Whitney from SRNA, Tricia Plumb from UT Southwestern, representing the CAPTURE study, and Lindsay Rechtman from McKing Corporation, representing the Long-Term Outcomes Project in the Biorepository. They are on the line and available to answer questions at the end of the session.

But before we get started, we wanted to review a few housekeeping items. All participants will be kept on mute to reduce background noise. As such, please share any questions by writing them in the Questions box on the right side of your screen. You should see a narrow box with an arrow, and if you expand that box, you will see where to write questions. The final portion of today's session will be dedicated to answering these questions. Selected questions will be read out loud for the presenters to answer.

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Thank you for your patience. At this time I would like to introduce you to today's presenter, Janell Routh.

DR. JANELL ROUTH: Anna, thanks very much, and good afternoon, everyone. Thank you so much for joining us today for the second parent session on AFM. It has been a very unprecedented year, given our current situation with the COVID-19 pandemic, and now increasing COVID cases across the nation. In the midst of a massive agency-wide response to the pandemic, our AFM team has remained strong and dedicated to our mission to conduct surveillance for AFM, to further our understanding of this disease, and to expand awareness and education to providers.

In addition, as burdened as our state and local health departments have been, our dedicated surveillance coordinators there have been working hard to ensure that all suspected cases of AFM are sent to CDC for classification.

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I do believe that one of the silver linings of the pandemic is that we have not seen an increase in AFM this year, as we might have expected given the historical patterns. So I'd like to spend the next 15 to 20 minutes walking you through our surveillance data for AFM, discussing our efforts to promote that distinction between AFM diagnosis and case classification. And then, finally, end with some research opportunities that are ongoing now for AFM. And then we'll open it up for questions for those listening, and hope we can get to as many as possible.

So before I jump into our surveillance data, I want us to take a quick moment and talk about the success of our AFM Vital Signs release in August.

Vital Signs was started in 2010, and is a monthly report on an important health threat. Our AFM report targeted specific audiences, like frontline clinicians, to get the message out, to recognize symptoms, and hospitalize immediately. We urged providers to remain vigilant for AFM, especially during COVID. We put out a scientific manuscript called an MMWR, a fact sheet, and then we updated our website. There was a telebriefing with Doctor Robert Redfield and lots of media outreach as well.

So the Vital Signs report actually led to over 1,600 media reports, including network coverage such as Time magazine and CNN. We were told this Vital Signs was in the top-performing reports since Vital Signs first started in 2010, and are really excited to see our objective of increasing awareness around the United States, including both the general public and providers, come closer to that goal.

I'll also point out that our Public Health Grand Rounds session this summer with Rachel Scott sharing her story had over 8,000 hits on the web.

And lastly, I did want to say a huge thank you to all of the families who shared their stories for our AFM Stories feature. We appreciate you opening your lives and helping tell the story of AFM through your perspective.

So, as you all probably know from our research earlier this year and ongoing outreach that we did this summer, we did anticipate another peak year for AFM in 2020, based on those previous trends we've seen in the United States. But as of October 30th, 2020, there have been only 25 confirmed cases in the United States. These numbers are much lower than what we have seen in previous outbreak years.

COVID-19 prevention measures such as social distancing, hand washing and mask wearing may have reduced the circulation of enteroviruses this fall. It's uncertain what this means for the remainder of 2020, but we do know that people are more likely to get infected with enteroviruses during the summer and fall months, and we are heading into winter.

When you look at previous outbreak years, you can see that our number of cases fall off pretty dramatically between October and November. But despite this, again, given this unprecedented nature of what we're seeing right now, we want to continue to focus intently on surveillance for all possible cases of AFM. And our team does remain prepared to respond, in case we do see that uptick.

Our national map shows these 25 confirmed AFM cases in 15 states. There appears to be no pattern to these cases, which again is consistent with what we have seen from previous years.

So many of you might have seen this slide before. Another way we do use our surveillance data is to monitor the number of reports of suspected AFM cases to help detect possible increases in AFM. The reported increases are then used to trigger what we would call an outbreak response, which is a term that we use at CDC to really mean that we increase and strengthen our staffing structure in order to respond specifically to that outbreak.

So I know this slide has been shown in previous presentations this summer, but I wanted to give you an update of where we stand. This figure shows the average number of reports received by week during peak years 2016 and 2018 in the blue line. So these are increases in reports of suspected cases. And you can see that increase starting in week 37, 38, which corresponds to the month of September, indicating that we are moving into an AFM outbreak. So that blue line was from our outbreak years of 2016 and 2018.

The number of reports that we did receive in 2019, which was a non- peak year — and we use this as our baseline — is shown in yellow. You can see that in a non-peak year, we don't get that increase in AFM suspected case reports. And then finally, the number of reports for 2020 so far this year is shown in red. And you can see that the red line mimics that baseline of 2019. So showing that we're really looking at a non-peak year, at least from our reports.

And I know, I think, looking at this information, the big question on everybody's mind is, "So we're not seeing an outbreak right now in2020. What do we think might happen in 2021?"

And I'll say up front that I don't know the answer to that question. We might expect it to be another non-outbreak year if that pattern of low number of cases in odd-numbered years remains, or we might expect because we didn't see an outbreak this year, we would see one next year.

You can be sure that we are going to be monitoring the circulation of enteroviruses, and EV-D68 specifically, moving into the summer months next year to help provide us with some information to be able to look for that potential rise in cases next year.

So I'm going to leave our surveillance data for a minute and talk now about the diagnosis and classification of AFM. Again, this is something that we have talked about over the past year, and I think it can still be very confusing to really understand what that difference is. "Why is my child being diagnosed with AFM but CDC is not classifying my child as AFM?"

So I did want to go through this one more time, because I know questions remain.

Clinicians diagnose AFM. So when a child presents with limb weakness, the clinical team goes to work. Diagnosis is based on full medical information. So that includes a medical history, examination, and diagnostic tests, such as the MRI that's usually done of the brain and spine, and a lumbar puncture.

The clinical team aims to be as accurate as possible, so that they can provide the best care and treatment for the patient. And that diagnostic process happens while the patient is in the hospital, because, you know, we need urgent action, treatment, and care for that patient needs to be started immediately. So the clinical team needs to determine that diagnosis, so that can start.

Classification, on the other hand, is what our team does here at CDC, once we receive information about the patient from the clinical team via the state or local health department. We use this information, including some of the information that was collected by that clinical team, MRI and neurology notes, and we apply that information to a case definition that is used to standardize AFM cases.

Standardization is very important for surveillance data. It allows us to compare cases from year to year, and it actually allows us to generate the graphs that I just showed you. And that means we're able to identify patterns in those surveillance data that allow us to make some conclusions about AFM.

Surveillance process can take time. You know, although we've made significant efforts to really improve the time period between when we receive the information and when we return the classification, it can still take time. And so it's why we emphasize that patient care should never wait for a classification to be made. We also emphasize that that diagnosis should never be overridden by a case classification.

So this is a new picture designed by our communications team to help explain the difference between diagnosis and classification, and the separate processes that are used for each. If you're like me, I'm a very visual learner. Sometimes I find that a picture is helpful to explain things that I can't really pick up just listening to an explanation. So I wanted to go through this slide.

In the middle is a graphic of a clinician who's shown in blue and a patient who's shown in purple. The clinician suspects AFM and should immediately hospitalize and begin a diagnostic workup, as shown on the left of the slide. And in that blue or teal color. Clinicians should immediately begin treatment and not wait for that case classification, as I just mentioned.

The right-hand side of the slide shows the steps for case classification, which are highlighted by that green color. After the clinician reports the patient to the health department, the health department sends information to CDC. And at CDC, as I mentioned, we review that information using our expert neurology panel. We assign a classification, and send the result back to the health department, who then communicates it to the clinician, who communicates it to the family.

Again, I am going to stress here one more time that this case classification should never impact patient care or treatment, and it should never override that clinical diagnosis. It is solely for surveillance purposes.

So I'm actually very curious to know what you think, looking at this graphic, whether it is actually very helpful to explain that distinction. And we would like to put it up on our website, but I'm asking if you have any feedback, please do share it with us. We would be most grateful, as you're the audience that we're trying to impact by some of this messaging.

So you could either enter some information or comments in the chat box, or you could always e-mail us at AFMquestions@cdc.gov, and let us know what you think.

So in preparation for the expected outbreak this year, but also to improve our overall surveillance processes, we have worked to streamline our case classification procedures to ensure both improved accuracy and quicker turnaround.

First, more neurologists were added to that review panel to increase our ability to classify cases in a timely manner, especially during an outbreak situation. This year, we added a number of new neurologists. And so we have a total of seven now that sit on our expert panel.

Second, a more seamless online system is now in place for uploading MRI images. This system has really cut down on the amount of time it takes to get MRI images from the hospital to CDC. It also allows our neurologists to view the images and discuss their findings with each other if there is a discrepancy.

And then lastly, the neurologists on this panel no longer have to review the entire medical record in order to make a classification. Again, we've streamlined what they need to focus in on for a case classification, including neurology notes and those MRI images. The neurology notes we use to confirm acute flaccid limb weakness, and then the MRI images to confirm that gray matter lesion in the spine.

So for the last piece of my update, I wanted to outline all of the research opportunities that are currently ongoing, both for newly diagnosed patients, and for those who have been diagnosed in the past. If you're interested in participating in research, there are several opportunities available.

Participating in these studies may not benefit your child directly, but the information gained will really help with future research that can lead to the development of diagnostic tools, treatment, and prevention measures down the road.

The two studies listed here are for children with new onset of acute limb weakness. Once hospitalized, families may opt to participate in one of these opportunities, depending on which hospital they've been admitted to.

The first opportunity is the AFM Biorepository, which is helping to build an anonymous repository of samples, consisting of blood, stool, a throat or nasal swab, and cerebrospinal fluid. These specimens will be used to better understand AFM and to further the research efforts.

The second is the NIH Natural History Study. I know, for those of you who listened to the Johns Hopkins Symposium this summer, this was really well described. It is ongoing across the

country, and currently, I think it's enrolled 10 participants. This study is also contributing to a biorepository of specimens. But they're going a little bit above and beyond to collect clinical information, and also diagnostic images, so they can build an MRI repository.

These data will help us better understand clinical patterns and progression of AFM, identify determinants of health outcomes, meaning are there factors that we can identify that lead to improvement in weakness, or are there factors that contribute to severe disease?

It will also help us understand what diagnostic evaluations are the most important for AFM, treatments that may be helpful, and collect information on the signs and symptoms of children with AFM. So again, we can increase and improve awareness across the country.

More information about these studies and how to participate can be found on our AFM website. And the address, I think, that Anna or somebody is going to put up in the chat box. But you can always go to our website and click on the link for parents, and these research opportunities will come up, including ways to get more information.

So here are another couple research studies that are ongoing with our team at CDC. I did want to let you know about them because you may be contacted by our team in the upcoming months and asked to participate. Again, participation is always voluntary and confidential. And we respect your wishes if you don't want to take part.

The first is a Long-Term Outcomes Project. And I know actually many of you have been asking for this information. We started to look at outcomes from our more recent cases and are now expanding to look back at cases both confirmed and probable, from 2017 moving all the way back to 2014.

CDC has funded McKing Corporation to assist some of the health departments with this project. Again, health departments are busy doing many things this year, and so McKing has been brought on for health departments that need a bit of assistance.

Parents will be contacted by McKing or by the health department, depending on what state you live in, and asked to participate in a one-time phone interview. And our tentative start date for this project is early 2021. Again, this is going to help us understand the long-term outcomes of AFM patients, and provide some information, again, that I know we've all been eager for.

The second project is doing some communications research with parents of children with AFM. CDC has funded Porter Novelli to facilitate these surveys. There'll be two online surveys, again in 2021. The first will be asking about information and resource needs for parents. And the second survey is to gather feedback about how CDC talks about AFM in our materials that you see online.

You know, we do really want to make sure that we're communicating about AFM effectively and clearly. And we're really asking for your help to ensure that we do this successfully. It's a very important thing that we do. We take it very seriously and would really like your help to make sure we improve those communications.

Finally, there are two research studies that are being led by some of our partners. I did want to mention these to make sure that the list is complete.

The CAPTURE study, many of you know and may be enrolled in already, started in 2014 and is led by our friend Dr. Ben Greenberg out of UT Southwestern. This is open to children ages 0 to 17 years at their age of illness onset, or within six months of their diagnosis. And it is studying the long-term outcomes of pediatric transverse myelitis and acute flaccid myelitis, both to guide future clinical trials for children with these diagnoses, and again, to gain information about outcomes.

The study is still enrolling patients. They do use imaging and treatment records from clinicians at diagnosis, and then every four months, families and children continue to report outcomes via interviews, quality of life surveys, and a secure telemedicine portal.

And then finally there's the CORE Transverse Myelitis study, which is for families and children six months after their TM or AFM diagnosis, to be able to share data and long-term outcomes via the SRNA registry. And I know both Rebecca and Gigi from SRNA have more information about these studies, or you could contact Patricia Plumb directly for the CAPTURE study.

All right, so as you can see, AFM remains a high priority for CDC, after all that I've shown that's going on in terms of research, communications and our ongoing surveillance. I wanted to say we are incredibly thankful that we haven't seen many new cases this year, and we certainly hope that that continues moving forward.

But despite not seeing a rise in cases this year, our team is working hard to ensure that we keep a careful eye on suspected cases and enteroviruses, both as the year comes to an end and also in 2021.

I really thank you all for your time this afternoon, and I hope this was useful to provide some data about where we stand with AFM in 2020, at least through October of this year. And I'd like to turn the presentation now back over to Anna, who's going to lead us through the question-and-answer part of the presentation.

But before, Anna, before I do turn it over to you, I did want to mention something. We did receive a few questions in advance of today's session that were related specifically to treatments. And we appreciate the questions very much, but I did want to let you know again that CDC is not involved with the diagnosis, treatment, or ongoing care of patients. Again, it's that distinction between diagnosis and the clinical management and the surveillance and case classification that we do here at CDC.

But we do want to make sure that those questions get answered and families are getting the help that they need. So I do encourage those of you with questions around treatment to reach out to SRNA directly. They have been really helpful in connecting families to other families or to clinicians specializing in those treatments, so that there can be ongoing dialogue. And I know

they'll be looking out for those questions, so thank you very much for submitting them, and I hope that will be a good outlet for you to get more information.

So Anna, with that, over to you. I don't know if we have any questions in our chat box.

ANNA OKULA: We do. Thank you so much, Doctor Routh. I'll go ahead and invite Rebecca, Tricia, and Lindsay to join us. So if you guys can unmute, we will now answer some of the questions we received ahead of time, and via the Questions box today. So Doctor Routh, our first question is: Is my child with AFM at higher risk for COVID-19 complications?

DR. JANELL ROUTH: Yes. So a good question, and one that we get often emailed to us here at CDC. At this time we don't have any evidence to suggest that children with AFM have more complications from COVID than children without AFM. But I know this is certainly an area of concern.

We might expect that children who do have complications from their AFM, particularly pulmonary complications, could be at risk. And so you know, again we're really advising families to be cautious, to listen to CDC advice around social distancing, wearing masks and hand hygiene.

You know, particularly as we move forward into the winter season, I think we are certainly confirming that we're seeing a third wave of cases across the nation now, and really want to make sure that everybody's staying safe.

ANNA OKULA: Thank you. Our second question: How does MIS-C compare to AFM?

DR. JANELL ROUTH: So MIS-C is another uncommon complication of a common illness. It stands for Multisystem Inflammatory Syndrome in Children — MIS-C — and it's an unusual complication that we see in children who are infected with COVID. It's similar in the sense that AFM is also an uncommon complication of a common viral infection like enteroviruses, but the two are very different.

MIS-C can have neurologic complications, including weakness, but we know that the weakness tends more from damage to the brain than from the spine. We don't have, again, any evidence at this time to think children with AFM would be more at risk for developing MIS-C, if indeed they did become infected with COVID.

ANNA OKULA: Okay, thank you. Our next question: Will EV-D68 circulation decrease enough, now with COVID-19 measures, that it will not be a problem again?

DR. JANELL ROUTH: That's a great question, and I would very much like to answer in the affirmative, but we don't know. We are still seeing circulation of enteroviruses. You know, we do know that the data show us that enterovirus circulation this year has been reduced compared to last. But we have seen detections, and in particular, we still see detections of enterovirus D68, which we all know is one of the main causes of AFM.

So despite the fact that we haven't seen an increase in AFM cases, and we certainly haven't seen an increase in enterovirus D68, like we have in outbreak years, we do know that it's still circulating. So I don't know what that means for next year. But again, I can tell you we're going to be keeping a very close eye.

We have multiple surveillance systems that will be able to look at enterovirus circulation, and in particular EV-D68, both at CDC and also in collaboration with our academic colleagues. So certainly starting in the spring, we are going to be watching closely to see what happens.

ANNA OKULA: Great. And following up to that: Are COVID precautions reducing transmission of enteroviruses, generally speaking?

DR. JANELL ROUTH: I think that yes, they are. In fact, they're probably reducing transmission of viruses in general, not just enteroviruses. I know that we're all sort of waiting to see what is going to happen with the influenza season this year, but we do know in the Southern Hemisphere, which has their influenza season reversed, there was very little disease and transmission.

So it will be interesting to see what happens this year, but I do think those protective measures are decreasing viral transmission, and it is something to keep in mind, you know, as we move forward.

I think a lot of the measures that we're using right now are onerous, and I — probably as much as you all are — looking forward to see my family again. It's been a long time. But, you know, certainly, the hand hygiene and the things — staying home when you're sick, those types of measures — have really, you know, brought about a nice change for us with AFM this year, and I would love to see that continue in the years moving forward.

ANNA OKULA: A little bit of sunshine. Our next question: Is the lack of spike in AFM cases possibly due to misdiagnosis? Or is it truly not spiking?

DR. JANELL ROUTH: A good question. I would like to think that it is not due to misdiagnosis. Again, we have done so much outreach this year to increase awareness and education around AFM starting in the spring. We've had countless webinars with professional organizations. We had the big Johns Hopkins Symposium, Public Health Grand Rounds and our Vital Signs releases I talked about. I think we have done a great deal to increase awareness across the country.

And I do think that clinicians are looking more carefully at children coming in with flaccid limb weakness due to those efforts. You know, again, that is… In terms of misdiagnosis, I think…

You know, this is not COVID, and this is something very different. It's very distinct, when you see a child with an arm or leg that is weakened, and it is something to take very seriously. So again, I hope that we've done a very good job targeting clinicians, and particularly those frontline clinicians, emergency room, and urgent care providers, to be able to recognize that, hospitalize and report.

ANNA OKULA: Great. Our next question: Every AFM case seems to be different. What are the standards being used for case classification, and what if you don't have an MRI?

DR. JANELL ROUTH: So, you know, again, as part of that increasing awareness and education around AFM and what to do when faced with a child with a weak limb, we have really emphasized that an MRI is an important diagnostic test in making that diagnosis. So I hope, as we are moving forward, we will see less and less children manifesting with AFM that do not receive an MRI.

If a child does not receive an MRI, it's very difficult to classify that case, and I would… As a clinician, it's very difficult to make that diagnosis, because it's that gray matter lesion in the spine that's important for both. It's important for… It's a diagnostic marker, and we use it also for our case classification process. So, you know, it's really one of the key pieces of information we need to make that case classification.

We… You know, again, that classification process is for standardization. We have, you know… Even though our case classification has changed a little bit, the definition from year to year, a confirmed case has really remained the same since 2014, and it is that, you know, person with acute flaccid limb weakness and that gray matter lesion that to us really signals this is a case of AFM.

ANNA OKULA: Building on that: Which clinician does the case classification go back to, and is it the one who reported it to CDC?

DR. JANELL ROUTH: Yes. And I think this is something that I will say we would like to work on: to make sure that that information is going back to the clinician who's taking care of the patient, but then ultimately to the family and the patient themselves.

It does go back to the clinician who reports the case. But in many instances, we're learning that at a particular hospital, that could be a variety of clinicians within that hospital. For some hospitals, it's the pediatric neurologist caring for the patient. In other hospitals, it's the infection control physician who is managing infection control across the hospital.

So, you know, we, again, need to make sure that we have measures to get that classification back. You know, if it goes back to that infection control doctor who may or may not have contact with the patient moving forward, that's a gap that we need to overcome. We've been thinking about many ways to do this.

And one may be to get the name of the primary pediatrician for the child. You know, we always think of that primary pediatrician as the medical home for a child, even though they might have many different specialists taking care of them. And so that might be a way to ensure that that information is always finding its way back to the family. We're working on it.

ANNA OKULA: Is there a date when an ICD-10 code may be available?

DR. JANELL ROUTH: I'm smiling because Robin Roberts has worked really hard to make this happen for us, and we are just so appreciative of her efforts. An ICD-10 code for AFM would really help us with surveillance efforts. Again, you know, the question about misdiagnosis. Having an ICD-10 code would really allow us, again, to boost our surveillance efforts and see where AFM is across the country.

So actually in September, the body of people met who control those ICD- 10 codes. When you want to implement a new code you have to give a presentation. Dr. Sarah Kidd from our AFM team gave a fantastic presentation to the group, and we are waiting now to hear whether they are going to approve that new ICD-10 code.

If it does get approved, it will be enacted one year from now. I know that sounds like a long time, but I guess it has to be programmed into multiple different places, and so we're really crossing our fingers that by October of 2021, we'll have an ICD-10 code in place for AFM.

ANNA OKULA: That's a positive update. Our next question: Which studies can people participate in who are two years out from diagnosis?

DR. JANELL ROUTH: So again, great question. Those first two that I mentioned, the Biorepository and the NIH study, are really for newly diagnosed patients, because we're trying to collect specimens and really follow them from their acute diagnosis out.

But certainly, the Long-Term Outcomes study is something that we would be very grateful if parents would be willing to participate in that effort. The communications research as well, it doesn't matter when your child was diagnosed, we really would like to hear from you about what you would like from us to better cope with AFM.

And the CAPTURE study and the CORE TM study, I am not entirely sure if they can be picked up two years out from a diagnosis. I don't know. Maybe Patricia or Rebecca, if you're on the line, you could say a few words about those.

REBECCA WHITNEY: Yes, absolutely. I can speak to CORE TM and say that that is for anyone with a diagnosis of AFM or TM, regardless of where they are in the timeline of diagnosis. So even if it was an infant, so just a clarification on the point that was made earlier. It doesn't have to be post six months from diagnosis. It's anywhere. So two years out, ten years out. We welcome that information. And I know Tricia can speak to CAPTURE.

TRICIA PLUMB: And yes, and thank you very much for having me today. This is Tricia Plumb. And yes, with the CAPTURE study, we would like to have them within six months of diagnosis, but with the CORE TM study, everybody is welcome at any time point.

DR. JANELL ROUTH: Great.

ANNA OKULA: Great. Thank you all. Our next question: How long does it take for a case to be reviewed and classified by CDC?

DR. JANELL ROUTH: A great question, one we get a lot. And, as I mentioned, we are doing a lot to try to improve that the timeliness of our case classification process. It does require many different pieces of information, both the neurology notes from the clinician as well as those MRI images, because again, that speaks to that case definition for AFM.

I would say it's probably the MRI images that take the longest, but we are hoping with our new online MRI system to overcome some of that delay. So I would say, on average, it takes about four weeks to complete the process after all of the information is received at CDC.

Again, we do go through a very rigorous process for case classification. It's reviewed independently by two neurologists on our panel. If they have the same classification, then we consider that to be the final classification. If their classification is discordant, then we do bring in a third neurologist to adjudicate the case. So if we do bring in a third neurologist, or the neurologists may ask for an additional piece of information to help with that classification process, it can take a little bit longer.

You know, again, this will probably be a good place for me to emphasize one more time that the classification of your child's illness by CDC should never one, override the clinical diagnosis, and it should never hold up treatment and care for your child in the hospital and after discharge.

ANNA OKULA: Thank you for that. Our next question: What are the outcomes of patients who have AFM?

DR. JANELL ROUTH: So we're working on it, and, you know, I can tell you a little bit anecdotally that we've heard there's a wide spectrum of outcomes for patients with AFM. There are some children who do seem to make a good recovery, but there are others we know…

Thinking of some in particular who have been really touched by this illness and are ventilator-dependent or in wheelchairs or both. And we would really like to understand why, you know, some children move on to show improvement, and others do not.

That's certainly something that we're hoping the NIH study will be able to help us understand in greater detail. Because again, a lot of this information is anecdotal, we are really moving forward with a more rigorous review of outcomes for all patients with AFM.

Again, we started this in 2018, and now we're moving back cases all the way back to 2014. The cases from 2017 back to 2014 will be a one-time interview, just to get a snapshot in time of what the child's outcome is. For our cases from 2018 and moving forward, we're actually collecting outcomes at three time points: two months, six months, and 12 months. Again, to better understand the nuances of recovery.

ANNA OKULA: Thank you. Our next question submitted says: Has any progress been made in understanding why this common virus causes issues in AFM kids?

DR. JANELL ROUTH: So thinking about why EV-D68, it sounds like, causes AFM. So again, common virus. In 2014 we really did see a large outbreak of EV-D68 nationwide. For the most part, it caused either mild respiratory illness, or in some cases severe respiratory illness, severe enough to be hospitalized. But you're right in… uncommonly this virus moved on to cause paralysis.

And I would say that is the question that we're all striving for: to really understand how this virus goes. You know, we think it's a respiratory virus, so how it's transmitted from the nose back to the spine, you know, that remains a question. How it infects those spinal neuron cells remains a question. There's lots of research ongoing right now about this.

And again, I think some of the most exciting research to come out of the past year, certainly, has been finding those enterovirus antibodies in the cerebral spinal fluid of children, letting us know that, you know, the virus was there. But again, the granular questions about how it specifically causes disease and why some children move on to get paralysis, while others don't. That's the big question.

And so, you know, I'm hoping as our community grows, and there's more awareness, we can start to answer those questions.

I want to say that every case, every child that gets reported to CDC, every child we receive information about, every child that we classify is important. Gives us information regardless of that final classification — confirmed, probable, not a case. Every child that we review sheds an important new piece of information for us. With a disease as uncommon as AFM, it's so important to get as much information as we can.

And we, you know, again, really thank the parents who have advocated to clinicians to be aware of this illness. We thank so much all of our organizations who have put this on the front burner over the past few months. So, even if we're not seeing an outbreak this year, I think that information is going to stick, and we will make sure it's fixed for the coming year.

ANNA OKULA: Our next question: If CDC does not give guidance on treatment, where does that come from?

DR. JANELL ROUTH: So, you know, treatment is really the purview of the clinical team, who is taking care of that patient. We at CDC are fairly removed from the patient bedside. And so, you know, it's up to the clinical team to really do that assessment, do that diagnostic workup carefully, and then apply the best measures of treatment that they know to the child's illness.

We have at CDC collected information from the literature and from our clinicians that we talk to regularly, including the AFM Task Force and the AFM Working Group to come up with what we're calling AFM clinical guidance. This document is posted on the CDC website, and it is a document that outlines the data that we have around specific treatments for AFM.

You know, again, with a disease as uncommon as AFM it's very difficult to do the clinical trials that we need to understand if a treatment is effective, or if one treatment works better than

another. We are hoping that the natural history study will shed some light on that. But in the meantime, we do have a clinical guidance document up online, and it does review the treatments that have been used for AFM.

I think, you know, I can say just as a summary: We don't really have data to support one treatment versus another. But that's where the subtlety of a good clinical team comes in. You know, again, Carlos Pardo and his AFM Working Group have done an amazing job getting a group of clinicians together that has really shared knowledge back and forth about how to treat patients.

And so there's also… One thing I will mention is the Clinical Portal that is on the SRNA website. Now any clinician who is taking care of a child with acute flaccid limb weakness can write into the portal and request a consult. And within 24 hours, somebody from Carlos's team, and them as well, will get back to that clinician with some expert advice.

So, you know, again, that diagnostic and treatment information is really coming from the clinical piece of this.

It… you know, maybe to use a bad metaphor, but it does take a village. I think it takes all of us working together to understand AFM. It's the clinical team that are treating the patient at the bedside. It's CDC who is looking nationally at surveillance efforts. And it's the parent group who is spreading the word out to other parents and to their clinicians to say, "Recognize AFM. It may be uncommon, but it's not going away."

ANNA OKULA: And building on that, you just teed up the next question well: Is there a plan for a vaccine?

DR. JANELL ROUTH: So, there is vaccine work being done right now for EV-D68. I know there's been some pre-clinical work that's been done at NIH right now. And I just heard, and I probably can't speak very well to this, but I can certainly get some more information to you by e-mail. There's a company in the Netherlands who was awarded a contract to work on an EV-D68-specific vaccine.

So I think it is in the works. People have recognized that this is a serious pathogen. They've recognized the severity and the devastation that it can cause in terms of AFM. And so I think it is really exciting that we are moving forward with prevention measures like this.

ANNA OKULA: Great. My next question is coming. All right. I just got the news that I think we have answered most of the questions. So thank you so much, Dr. Routh. Thank you, Tricia Plumb, Rebecca Whitney, and Lindsay Rechtman as well. We really appreciate your time today.

So with this, this concludes our session. For those who have joined us, once you exit, you will be brought to a screen and asked a series of evaluation questions. These questions are completely voluntary, and any answers will be used to inform and improve future sessions.

AFM Parent Session Transcript
November 12, 2020

Thank you all for joining us today. Just a reminder that the recording and a transcript of this session will be on CDC's AFM website. If there are any questions that did not get answered today, or if you have any following today's session, please feel free to e-mail the webinar address or the e-mail address AFMwebinar@porternovelli.com, which is part of the invitation that you received, so you can find that there. We'll work with CDC to get answers back to you.

Thank you all for joining. Thank you for tolerating the inevitable COVID technology issues and the delay. If it's not who's on mute, it's something. So, thank you, Doctor Routh. Thank you, everyone, for joining. I hope everyone has a wonderful and safe rest of your day.

DR. JANELL ROUTH: Thanks, everyone.

ANNA OKULA: Take care.