



The Role of CDC and Public Health in AFM Surveillance

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Rebecca Whitney: [00:00:00] Welcome to the SRNA Ask the Expert podcast series, a special edition in collaboration with Centers for Disease Control and Prevention, Division of Viral Diseases, or CDC. This podcast is entitled CDC and the Role of Public Health and Acute Flaccid Myelitis, or AFM. My name is Rebecca Whitney, Associate Director of Pediatric Programs with Siegel Rare Neuroimmune Association, or SRNA.

[00:00:29] SRNA is a nonprofit focused on support, education, and research of rare neuroimmune disorders. You can learn more about us on our website at wearesrna.org. For this podcast, I sat down with Dr. Benjamin Greenberg of the University of Texas Southwestern Medical Center, Dr. Jenell Routh of CDC, and Emily Spence Davizon of the Colorado Department of Public Health. Dr. Benjamin Greenberg received his Bachelor of Arts degree from Johns Hopkins University and his Masters Degree in Molecular Microbiology and Immunology from the Johns Hopkins School of Public Health in Baltimore, Maryland. He completed his residency in neurology at the Johns Hopkins Hospital, and then joined the faculty within the division of neuroimmunology.

[00:01:18] In January of 2009, he was recruited to the faculty at the University of Texas Southwestern Medical Center, where he was named Deputy Director of the Multiple Sclerosis Program and Director of the new Transverse Myelitis and Neuromyelitis Optica Program. Dr. Greenberg is recognized internationally as an expert in rare autoimmune disorders of the central nervous system.

[00:01:41] His research interests are in both the diagnosis and treatment of acute flaccid myelitis, transverse myelitis, neuromyelitis optica, encephalitis, multiple sclerosis, and infections of the nervous system. He currently serves as the Director of the Neurosciences Clinical Research Center and is a Cain Denius foundation scholar.

[00:02:03] Dr. Janell Routh graduated from the UCSF/UC Berkeley Joint Medical Program in 2004 and UCSF Pediatric Residency Program in 2007. For the next three years, she practiced pediatric HIV and general tropical medicine in Malawi with the Baylor International Pediatric AIDS Initiative. She returned to the US to start the Epidemic Intelligence Service (EIS) fellowship with CDC in Atlanta in 2010. She is currently in the Division of Viral Diseases as the program and team lead for acute flaccid myelitis since 2016, and most recently worked on the Vaccine Task Force to help COVID-19 vaccine implementation.

[00:02:50] So thank you so much to each of you for joining us on today's podcast. I'd like to begin with Dr. Janell. Could you give us a brief history of CDC and what the role of CDC is, what it means to the average American family? Just so that we have an idea, it's been obviously in the news more and more in the recent past due to the pandemic. But many families often don't find themselves having to even think about CDC or talk about public health until they're facing a diagnosis such as acute flaccid myelitis. Could you start us off with a brief overview?



Janell Routh: [00:03:34] Sure, happy to. I, I was laughing because I think this is the first time in 10 years my parents actually understand what I do at CDC after CDC has been in the news so much around COVID-19 and the response. So CDC is an agency under the larger umbrella of health and human services. Overall mission essentially is to enhance the wellbeing of, and the health of, Americans. CDC engages primarily in health promotion, prevention of disease, injury, and disability, and preparedness for new health threats.

[00:04:10] We're composed of, of wide variety of people from epidemiologists to clinicians, to behavioral scientists, all working in that realm of public health. I myself trained with the epidemic intelligence service, which is a fellowship within the Centers for Disease Control that takes medical professionals, veterinarians, people from diverse backgrounds, and trains them in epidemiology, which is essentially, you know, you might hear about us described as disease detectives. But what we're doing is searching for the cause of disease, identifying people who may be at risk of disease, and then determining how to prevent and control disease outbreaks.

Rebecca Whitney: [00:04:55] Okay. Thank you very much for that. That's very helpful. And CDC hasn't always necessarily been synonymous with rare disease but has certainly evolved to include rare diseases and disorders in recent decades. When did CDC recognize and become involved in surveillance of acute flaccid myelitis?

Janell Routh: [00:05:19] So that was in August of 2014 when CDC became aware of a cluster of cases of children with acute flacid weakness and findings on their MRI - magnetic resonance imaging - in their spine that were consistent with what looked like polio.

[00:05:42] And this cluster was presented to CDC. And that's when we became involved in the investigation. I actually joined the AFM team in 2016. I wanted to turn to my colleague, Emily Spence Davizon, who actually works at the Colorado Department of Public Health and Environment.

[00:06:02] And she was actually present in 2014 when those first cases became, were brought to light. So, Emily, I wondered if you could maybe share some of that initial response to that cluster of cases.

Emily Spence Davizon: [00:06:18] Sure. Thanks Janell. So, the late summer and early fall of 2014 were sort of a wild time in public health. If you remember, the AFM Signal emerged against the backdrop of this nationwide severe respiratory outbreak among children driven by enterovirus-D68.

[00:06:36] And also, concurrently, there was the Ebola outbreak unfolding in West Africa and then the really massive, you know, US public health and medical response. And I had just started in public health. I don't actually think that the, the ink was dry on my diploma yet. So, I sort of walked backward into AFM because literally I had started the health department about a week before and I hadn't been roped into other projects yet.

[00:07:03] So I had the availability to work on AFM. And we were communicating a lot with our partners at Children's Hospital Colorado, because they had noticed this influx of kids who were really clustered in time and space, had this preceding respiratory illness back in 2014, and had this acute onset limb weakness.

[00:07:25] And I don't think I was aware at the time that we were sort of describing a new condition. I think just mostly my eyes were like really big and kind of taking it all in. And I do remember being in a room, I think on a conference call, when folks were debating, you know, what do we call this?

[00:07:44] And so that's, that's kind of striking to me as someone who was like an entry level employee getting to actually be a fly on the wall during some of those conversations. So, I, I really had the distinct privilege of working with our clinical partners, our CDC partners, and really since, since 2014, since the beginning. So, pretty special.



Janell Routh: [00:08:06] Great. And getting back to your point, right? The reason that we actually named it acute flaccid myelitis was to distinguish it from the paralysis caused by a poliovirus, because we knew this wasn't poliovirus causing these cases. So yes, at, you know, at CDC, we worked with partners like Emily to put on a national call for cases.

[00:08:26] So, you know, the original cluster was discovered in Colorado, but certainly we wanted to know, were there any other children being affected across the nation? So, we put out a national call for cases, and by the end of 2014, we had collected 120 cases of children that had this condition. And then that sort of catapulted us into a standardized national surveillance system that was started in 2015 to track AFM moving forward.

Rebecca Whitney: [00:08:55] Okay, thank you so much. And one thing I wanted to clarify as well, as we often hear of another federal entity that has a role in public health and that's NIH, or National Institutes of Health. Can you clarify a bit how your role is different, how you work in conjunction with NIH as it relates to AFM surveillance?

Janell Routh: [00:09:19] Sure. So, you know, as I mentioned, CDC is an agency underneath health and human services. So is NIH, but are our missions, while complimentary, I think are slightly different. Again, CDC is really focusing on public health and prevention whereas NIH is actually the largest research arm focusing on applied biomedical and behavioral research.

[00:09:41] And I think Ben could probably talk a little bit more about the research that is conducted at NIH because our clinical partners often collaborate with NIH in order to do some of that clinical research that NIH does so well. But you know, we certainly do collaborate on the information provided by CDC on public health needs, actually informs the policy and research direction that our NIH colleagues set every year.

[00:10:10] I guess one really good example of our collaboration is that NIH Natural History Study which was started in, I think, Ben, if I'm not mistaken, 2019 after, you know... so CDC had been tracking AFM for five years and it was recognized that we needed to do further research into the clinical presentation, treatments, and outcomes of AFM patients.

[00:10:35] And so NIH put out a research project that I think has enrolled now 35 sites, 35 pediatric hospitals across the country, in order to help standardize the information that we're learning about our patients with AFM.

Ben Greenberg: [00:10:51] Yeah. And, and I agree with everything you said. And one of the distinct, other distinctions is, you know, while the NIH will address research in public health issues, it's not contained to public health issues. And so, the research portfolio supported on the campus of the NIH, or funded elsewhere in the country by NIH funds, runs the gamut of, you know, basic science, cancer, neurology, allergy, immunology, infectious diseases, a whole host of things that may or may not have public health implications, whereas the Centers for Disease Control and their partners at the state and local levels are just steeped in everything public health related.

[00:11:36] And so there are some differences in the portfolio between the two. But as an outsider, as somebody who's collaborated with both institutions, I routinely find them sitting at the same table when there was a public health related issue that comes up and making decisions on what types of work may happen in one or the other agency, so that there isn't duplicative efforts or wastes of resources. And so while the CDC performs outstanding research on an annual basis around those public health issues, there's a discussion with the NIH of who can and should be doing what to cover as much ground as possible.



Rebecca Whitney: [00:12:14] Okay. Excellent. Thank you for those clarifications. A couple of other terms essentially that we hear about acute flaccid myelitis surveillance are 'nationally notifiable' and 'mandatory reporting.' Can you also assist in clarifying what those two mean? How they're distinctly different? What is currently in place for acute flaccid myelitis?

[00:12:44] Dr. Janell, can you start us off?

Janell Routh: [00:12:46] Yes, I'll start us off and certainly welcome others' input. The term 'nationally notifiable' refers to diseases or conditions for which it's called the Council for Territorial and State Epidemiologists. We abbreviate that to CSTE. So CSTE and CDC collaborate to determine which specific diseases and conditions should have voluntary notification of that case information, patient information, from states to CDC.

[00:13:17] So that's what we talk about when we say nationally notifiable. But the point that I want to make is that even when a disease is considered nationally notifiable, reporting of data to CDC is always voluntary. When a disease is reportable, that really means that there's a state law mandating reporting to the state health department.

[00:13:39] So a reportable disease would have mandatory reporting to the state, but, but not necessarily to CDC. So, in the case of AFM, for example, mandatory reporting of AFM surveillance occurs at the state level, not really up to the CDC level. We know though that each jurisdictions have some mandate to report AFM case data up to CDC. So, you know, people often ask me, do you think there would ever be a case missed?

[00:14:12] Would a case be reported to a state, for example, that would then not get transmitted to CDC. And I actually don't think that's the case. We have a really incredibly strong network of vaccine preventable disease coordinators in every state. And they are incredibly good about contacting us the minute they hear about a case.

[00:14:33] So again, not every state has AFM reportable, but every state does have some provision to make AFM notifiable within that state. And then, like I said, those vaccine preventable disease coordinators do tend to let us know the minute they hear about a case.

Ben Greenberg: [00:14:52] Yeah. And so, if I can interject on that, I, I think one of the things to recognize in that system is the weak link in the system is actually in the clinical trenches. Because, as Janell said, once the report gets made and every state and locale has a slightly different process for doing that.

[00:15:07] But once that activation occurs, in my experience, the integration of data between the state and the national level actually runs in a very smooth operation with differences from location to location. And we have to admit, these are all resource dependent. The better that our local public health departments are staffed, the better the service we get.

[00:15:27] And that's just true in anything we do. But the weak link has been around getting clinicians to recognize acute flaccid myelitis, and then initiate the reporting. So, one of the things that is very unique about this condition is the report is purely dictated by the clinician. It isn't a lab test that triggers it.

[00:15:52] So, for example, and I think it's fair to say if Janell, you can help me with an example. Emily, you can help me with an example. If there was a positive anthrax culture somewhere, the lab, the microbiology lab would get triggered to report, 'we have a positive anthrax culture' to the public health department.

[00:16:14] It wouldn't matter if the clinician recognized anthrax was reportable or not. There's a safety net



within the lab. Acute flaccid myelitis is one of the few conditions, there are, there are other examples, but one of the few conditions where the clinicians have to be aware of the importance of reporting it.

[00:16:32] And so a lot of the work we've done locally in, in my state of Texas and then in partnership nationally with Janell and the CDC, has been around raising public awareness, not just amongst families, but amongst healthcare providers so they know when they see even a possible case of acute flaccid myelitis to report it, so it can be adjudicated to decide what the true epidemiology is. But it's for a rare disease, you, you can set up the, the best network in the world of public health officials. But if the clinicians aren't recognizing what they're seeing or aren't acting on what they see, then that's what limits the data.

Janell Routh: [00:17:11] Emily, did you, do you want to talk at all about how you raise awareness of the clinicians within your state?

Emily Spence Davizon: [00:17:19] Sure. That's a great question. So, to Ben or Dr. Greenberg's point, AFM is not, there's... you know, there's no lab component to the case classification or the reporting criteria for AFM, which puts it in a, a small minority of reportable conditions, both in Colorado and I think nationally, where you can't rely on lab-based reporting. And these days, the lab-based stuff is actually pretty slick in a lot of cases because there's actually something called electronic lab reporting right now.

[00:17:50] So all of those major commercial laboratories, they just send us data packets like daily, if not a couple of times a day. And so, for things like salmonella, for example, where you've got a positive culture, that's a really well-worn, you know, slick system for getting case reporting. So, it's, it's a little bit different when you have to pivot to raising awareness.

[00:18:13] And you're really concerned about under-reporting. So, for example, we have access in Colorado to a database of providers and their practice locations, which is actually, it doesn't sound innovative, terribly, on its face, but it somewhat is because we have data in Colorado to show, but I think something like 2% of providers change their practice location every month in Colorado.

[00:18:36] So over the course of a year, that's upwards of a quarter of providers may have moved. So, we have access to this database that allows us to have relatively real-time contact information. So, for example, in previous years, we've sent what we call a 'dear provider' letter to specialists who we thought were most likely to encounter a patient with AFM.

[00:18:55] So radiologist, neuroradiologist, infectious disease folks, and neurologists, and that's one way we've done it. Some other stuff we've done is collaborating with our clinical partners at Children's Colorado to do provider outreach and education. So, sort of like grand rounds kinds of things. So, providers really talking the language of providers to other providers, because I'm not a provider.

[00:19:18] You don't want me telling you, you know, how to do like a history of physical. So that's been really important to tap into partnerships with people who are not necessarily like directly public health. As Janell mentioned, you know, our experience in Colorado back in 2014 really was a motivator to add acute flaccid myelitis to our list of reportables that's determined by our Board of Health. So, I think AFM has been reportable in Colorado, what we call 'explicitly.'

[00:19:47] So it's, you know, it's listed as like salmonella, AFM, polio, you know, measles, all that stuff. It's been on our list since 2015, I think, based on our previous experience. So there was a, you know, a fair amount of interest in making that explicitly reportable in Colorado.



Janell Routh: [00:20:03] Right. Thank you. And another, a number of other states also have it explicitly reportable as well. Other states might use the term like 'reportable under a suspected case of polio.' So other states will use that in order to mandate reporting. And then yet others use the the term, you know, a disease of unusual origin or an unknown origin in order to report. So, there are multiple different ways an AFM case can get reported to the health department. But again, once it is reported to the health departments, it is, CDC usually receives that information.

Rebecca Whitney: [00:20:40] Okay. Thank you so much. And obviously, in talking through this, tracking and understanding AFM is a community effort, right?

[00:20:49] It takes several different hands at different points during a diagnosis, happens at the clinical level. And I thought, Dr. Greenberg, if you can talk a bit about what your role in the clinic, when you are facing a possible, a family who's looking at an acute flaccid myelitis diagnosis. From that perspective, what is, what are those roles and responsibilities of the, the clinician as well as maybe academia in getting it to that next level? And then we'll hear more from Emily as far as how we work up to CDC for those reports.

Ben Greenberg: [00:21:31] Yeah. So, this is probably one of the areas of medical education that I think is actually lacking in a, a uniform way across the nation. So, we're trained as physicians, as medical doctors, in a very appropriately bubble-focused priority of the patient and the family.

[00:21:52] They, above all things else, everything we do, everything we should be doing day in day out, moment to moment, is to put the patient's safety, wellbeing, and best possible outcome around health and quality of life as our priority. So, every day we wake up and go to bed with that as a priority. But, and, and that's ingrained into us throughout our training, and we take oaths around it, et cetera.

[00:22:13] But, we are also an extension of the public health infrastructure of the nation. And we pick up that responsibility in little ways that aren't as formal as they should be. We learn about mandatory reportable conditions, reportable conditions, but it is not always ingrained into us, into myself and our colleagues, the critical role we play for patients for whom we're never going to meet. So, I not only have an obligation to the person in front of me, but I have an obligation to everybody in the community to make sure data is moving in a seamless fashion in order to protect the health and wellbeing of other individuals.

[00:22:58] And that's, at its core, what public health is. I loved the bumper sticker where I did part of my training, the Johns Hopkins Bloomberg School of Public Health, their bumper sticker was, 'Saving lives millions at a time.' And, and that's the, the notion of, of public health, of really elevating at a community, at a national, and a world level of protection, but it can only function if it has data.

[00:23:26] And so my responsibility in the trenches, so to say, is being aware. Understanding what diagnoses should be considered, and of the diagnoses that may have a public health implication, reporting them to individuals who have a local, state, or national standing to survey for other cases. I'm not an epidemiologist.

[00:23:53] And so, me sending off an email to my colleague, which is what was going on back in 2014, et cetera, "Hey, have you had a case? Have you had a case?" And all of a sudden, we realized was 30 cases at the same time in different hospitals is not a very efficient or fail-safe way to manage public health. And so, we rely on our partners at the state and local level and the national level who've been trained, that the training Janell got is something I have not received.



[00:24:20] And it makes all the difference in the world. So, it's, for us it's recognition. And then I would say erring on the side of reporting versus not reporting that our, our colleagues like Emily can read the data and put cases into buckets in terms of definitely, not definitely, or we need more data pretty quickly and efficiently.

[00:24:42] And so I've never met a public health officer who was annoyed with me for reporting a case that didn't turn out to be acute flaccid myelitis. We, we expect it, it's part of the issue, but we have to get people to do it. And what I'll just end by saying is, that is not a formerly trained part of my job.

[00:25:02] And it's just, unfortunately, we put economics into everything in the healthcare systems. It is a non-reimbursed part of the job, but it is part of my duty as a healthcare provider. And so, it's just making sure that all of our healthcare providers embrace it and then know what to do with the information who, who to call or at least who to ask.

[00:25:25] And then we turned the keys over to our local colleagues like Emily to take it from there.

Rebecca Whitney: [00:25:30] Yes. Excellent. And that's exactly where we'd like to go. Next is Emily. What is your role in the state and local health departments as far as collecting that information from the clinicians and moving that case forward?

Emily Spence Davizon: [00:25:48] Yeah. Thanks. That's great. I think Ben did a great job of describing the complementarity that's involved between, and the collaboration that's necessary and also frankly, like, very rich between public health and clinicians. Because like, like I mentioned earlier, like I can't go out and examine a patient. A) it's illegal and B) like, I'm not skilled at it.

[00:26:10] Right? Like I can't, you know, do like a differential. That's just not within my, my scope or my remit. But what I can do is take those case reports that come in from clinicians. And we at the state level, we're sort of this bi-directional conduit, I would say. So, we pick things up from the local level, whether that's a local public health agency, a parent, or a provider, we, you know, do some cleaning or some additional analysis or data gathering.

[00:26:39] And then we direct that up to CDC. And then, you know, we get things like case classifications and lab results back. And that's actually, one thing I really enjoyed about being at the state is that bi-directional flow of information and data. And just to riff on what Ben said, like, I love phone calls.

[00:26:56] Like I think I'm speaking for a lot of like vaccine-preventable epidemiologists when I say like, we love to help people. That's why, so like, if someone has a question because it's like, 'Where do I get measles testing' or 'where can I test for enterovirus in this patient I think might have AFM' that's often something where public health really has a concrete role to help.

[00:27:14] That may be a little bit outside of the practice of clinical medicine, because those types of things, you know, don't always impact patient care. For example, whether that virus is enterovirus-unknown or enterovirus-D68, that's not necessarily to my understanding, you know, going to direct clinical care.

[00:27:32] So that's one of the really nice complementarity things that I enjoy. Speaking of testing, so we help board on specimens for specialized testing at CDC. CDC has an amazing, super nice crew of lab folks who have always been there when I needed them. And they help us talk through technical things.

[00:27:53] So we pretty much exclusively worked with what are called residual specimens that we request. And we sort of request those under the auspices of the umbrella of this is a public health investigation, in



our case in Colorado for reportable condition. So once the clinical workup of the patient is done, we request their specimens for sort of like public health surveillance testing, because we don't want to do anything that would interfere with the clinical workup of that patient.

[00:28:20] And then for communication with clinicians and families, I'd say historically, we've had a lot more communication with providers because it was a little bit more like, 'yes, we're seeing this commonly right now,' or 'no, we're not.' We would talk them through what we needed for them for reporting, because AFM, unlike say like salmonella, for example, there's a lot more medical record documentation that needs to happen for that case to be classified and fully reported, which is maybe not the same with other conditions.

[00:28:51] And then we would, of course, be communicating with the clinician and the care team about sort of the, the reporting process, when we would expect the case classification back. I will say one change that I think is important and really meaningful is, previously, so public health, we would, you know, be doing these things sort of in the background.

[00:29:10] We would be requesting specimens, filling out forms, requesting medical records. So, we didn't really necessarily conduct like a case patient interview. And sorry I keep bringing up someone else, but you know, in a salmonella investigation, you'd be saying, "Oh, did you go to the picnic? Yes, no. Did you eat the potato?"

[00:29:24] So yes, no. And you need to ask the patient that way because that's not necessarily going to be in the medical records. So, one important change in the last, I think, is it two years we started doing brief functional follow-ups with patient and patient families at 60 days, 6 months, and 12 months.

[00:29:42] Whereas previously we didn't really have a system set up to do that again, because most things in infectious disease, public health are sort of these acute illnesses that resolve somehow within a very short period of time. But AFM again is, is different in a lot of ways. And so now we do have a little bit more interaction with families and we're able to answer their questions about the epidemiology of, of AFM and sort of how that surveillance process works.

Rebecca Whitney: [00:30:09] Thank you so much. And once that information, once everything, if all of those pieces are falling into place and the communications are moving their way up to, to CDC, I, I think it's helpful for families to know that when that case is presented to CDC, that it does not include personally identifiable information, is that correct?

[00:30:35] And once a decision is made as far as how it fits, what the case definition is, how is that communicated back? That's through the health department and then to the clinician, is that correct? Do I have that right?

Janell Routh: [00:30:51] That is correct, Rebecca. That is the way it is supposed to happen in a perfect world. And I think we are working to, to make that more perfect with every year that passes. I know there has been some communication challenges in returning those case classifications, but we are working to make sure that it in fact gets back to the family because I know that's a very, it's a very important piece of information for the family to have.

[00:31:18] I wanted to say, I really appreciate the way you've sort of walked us through both Ben's responsibilities as a, as a clinician and diagnostician and how that information gets transmitted to then the state health department and, and Emily's conversation about that. That's an important distinction, right?

[00:31:36] Because I think, as our listeners are hearing, that information flow takes time. And so, by the time information does make it to CDC, in order for us to make that case classification, you know, we want



the patients to be diagnosed and their clinical management underway. So, it's why we really insist on that separation between AFM diagnosis and the AFM surveillance case classification, which happens later.

[00:32:06] It, you know, it can happen two weeks later, even a month later, sometimes it takes for us to return that case classification. And we absolutely would not want a clinician to wait for that surveillance case classification before moving forward with diagnosis and treatment. So, I definitely wanted to make that very clear.

Rebecca Whitney: [00:32:25] Well, thank you, Janell, for that distinction. And that leads me to another question. [00:32:32] As far as the differences between surveillance definitions and what a clinician may provide as a diagnosis of AFM or perhaps another related disorder. Can you speak briefly about the surveillance definition, who uses it, and then, Dr. Greenberg, too, if you could maybe talk a bit more about diagnostic criteria in AFM?

Janell Routh: [00:33:02] Sure, but I can actually even pick up kind of from where we left off before. You know, once then Emily receives all of that information, the medical records and the specimens, all of that does get sent to CDC. And to use the salmonella analogy, if, if it was as easy as salmonella, we would have a laboratory test that confirms that illness.

[00:33:25] And then what CDC really does is collect those different pieces of information from the states. And then, when we provide a national overview, what that national look at what this, what this disease is showing across the country. AFM, again, is very different. We don't have a laboratory test for it.

[00:33:46] So when we do receive the medical information, as you said, deidentified, so we do not get any personally identifying information, but we do get medical records and the images, those MRI images. We use those to make the case classification. And in order to do so, because again, we don't have a laboratory test, we have a panel of expert neurologists who review the cases in order to make that case classification.

[00:34:10] So we're really using that process rather than a laboratory test to, to return that, that classification, which can differ from a diagnosis. And I think, you know, again, this is something that a lot of our parents have questions about. You know, 'why was my child diagnosed with AFM, for example, but the surveillance case classification came back differently?'

[00:34:37] And I might turn, I, Emily, she and I have known each other for a number of years, and she has this fantastic analogy about a cookie cutter, and I can never get the words right. But she does a really nice job of explaining exactly what that surveillance case classification is and how we use it. So, Emily, I thought maybe I'd turn it over to you to really explain that.

Emily Spence Davison: [00:34:59] Thanks. Yeah. So, I think in pictures, so I often try and describe the picture that I have in my brain to other people, whether that's an epidemiologist or a parent or a family. And so, for us, the surveillance definition, those, those case definitions that are agreed upon by the Council of State and Territorial Epidemiologists, right?

[00:35:17] Those things that are supposed to trigger reporting. So, we get, you know, a report from a clinician. And what I then do as an epidemiologist is I hold up a cookie cutter to the patient's medical record. And the cookie cutter is our surveillance case definition or our reporting criteria. And if that fits whatever is in the medical record, then we have a case that we're going to count that we're going to report to CDC, that we're going to, going to classify.



[00:35:47] And so that's so that we can make sure that we're accounting things consistently across space and time so that we can detect trends or increases or decreases, changes in epidemiology. But that cookie cutter is, is relatively rigid, I would say. And I have the sense that it's a little bit different in clinical medicine.

[00:36:08] I don't think... And I also should specify that the cookie cutter analogy is, is sort of thinking about things on population level as well, right? That's why that's there to just try and standardize things across that like 10,000-foot view. Whereas I, again, I have a sense it's different when you're standing in front of an individual patient. So maybe I'll pass it to Ben.

Ben Greenberg: [00:36:28] Yeah. So, while Emily lives in a world of, of cookie cutters, I live in a world of Play-Doh where things are much more malleable. And so, you know, there, this gets into the intersection of the science and art of, of medicine.

[00:36:48] And so, if you take any medical event, technically, if you take almost any event that we experience as humans, there's a fancy term of a Gaussian distribution of, of how people are. So, for example, height. There is an average height of men and women in the United States. And if you are seven feet tall, you are an exception to the rule, but you're, you still have height.

[00:37:14] You still get measured. But you're, you're unique versus the average, which is whatever it is. 5'8", 5'9", whatever it might be. And so, for a lot of definitions for reporting purposes, it's so hard to pick up on the outliers that there are definitions made to capture the overwhelming majority of cases, but you don't want to miscount.

[00:37:38] So we wouldn't want to include people who don't have acute flaccid myelitis in the count. So, we have to set some sort of definition because if we enroll people who stubbed their toe and they came in limping, but it was from a stubbed toe, that would really throw the data off. So, so we exclude everyone who stubbed their toe. And you start making these rules to create the cookie cutter that Emily talks about.

[00:38:03] As a clinician, I recognize that sometimes there's going to be an outlier. Maybe they stubbed their toe and have acute flaccid myelitis. So that, that rule that we put in to exclude bad data, very rarely may end up excluding an actual case or not including an actual case. And so, as Janell said, as a clinician in the frontline, I'll turn to some families and say, while you don't meet the cookie cutter definition for the following reasons, I am still diagnosing you with acute flaccid myelitis.

[00:38:34] And in terms of your care, and in terms of, of your diagnosis, this is what I believe to be the explanation of, of what happened. And this is emotionally and psychologically and intellectually a very tough exercise for everybody - the epidemiologists, the clinicians, the patients, and the families. Because we, we prefer a world where everything lines up. But in reality, the job, the task that we have from a public health and epidemiology perspective is different than the job I have as a clinician.

[00:39:10] And so my job is to treat the patient in front of me as best I can with the best data I have, even if they don't fit the cookie cutter mold. But Emily and Janell have an extremely important job to make sure from a national, well local, state, and national perspective, we get the best possible data we can so that we can make big national decisions about how they handle different public health issues.

[00:39:36] So we work in partnership, but we have a different, albeit overlapping, jobs. And so, it can be tough, but we try to navigate this with families. And then we on the trenches try to educate our clinical colleagues around clinical judgment, around diagnoses for those outlier cases. But the importance of even reporting those who don't fit the cookie cutter perfectly, because one of the things we do with Emily and Janell on a regular basis as a community, as a, as colleagues is revisit the cookie cutter definition.



[00:40:11] And we, we go from year to year and say, does that shape still fit what we're seeing, or has the arm grown out a little bit and we need a slightly different cookie cutter to make sure we're getting the best data captured possible? So, it's an organic process that evolves over time. And it's, it's that perfect intersection between art and science.

[00:40:33] The conversations at meetings used to be face-to-face, now video meetings, where we get to describe to Janell and Emily what we're seeing in the trenches and our colleagues get to describe it. And we all get to sit back and say, 'perhaps we need to tweak the definition,' is an extremely important process over time to make sure we're getting the most accurate cookie cutter possible, knowing it will never capture a hundred percent of cases.

[00:40:58] And, and it's, it's okay if it doesn't, if we're 95% accurate, that, for a public health perspective, that's great. And we don't want that 5% to emotionally, or from a care perspective, harm families who are going through this process, as long as the clinicians are acting on their best judgment.

Janell Routh: [00:41:20] Excellent. And, Ben, I'll say, a perfect example of that was the transition of the case definition from 2014 to 2015, where in 2014, we were focusing on pediatrics, but again, upon revision, then communication and discussion with neurologists across the country, in 2015, we opened that case definition up to people of all ages, recognizing that there are, occasionally, uncommonly, but there are adults who also get AFM.

Rebecca Whitney: [00:41:49] Excellent. Thank you. Thank you all very much for joining me today. Sincerely appreciate your time. Are there any last notes you want to make sure folks are aware of before we wrap up today's podcast?

Emily Spence Davison: [00:42:06] If I could take one minute, and I want to go back to something Ben said earlier about sort of the, the room for increasing awareness among clinicians and how that's around public health reporting and, and just sort of all the complexities around that. I did want to mention that, you know, one of the reporting criteria for AFM is a radiologic component, right?

[00:42:31] It's that MRI imaging. And one thing that I realized a couple of years into this work is that, you know, while your ED clinician might be familiar with dog bites are reportable to public health, or, you know, 'Oh, there's this measles, I need to call public health' or your pediatrician, you know, the same thing. In my experience, radiologists are not as familiar with, you know, that aspect of reaching out to public health and even like, is that allowable? Is that okay? Because sometimes folks don't always know that HIPAA, the privacy law that lots of folks are familiar with, you know, actually has provisions that say, yes, you can provide confidential information. You can provide protected health information to public health.

[00:43:16] And in Colorado, you have to do that, right, for things that are on the reportable conditions list. So, one thing that I think we're exploring, which I think is new and interesting is, you know, how do you contact radiologists? How do you do that outreach? How do they want information? Because I think that that's another avenue that we can look at for familiarizing folks with the reporting criteria for, for acute flaccid myelitis.

Ben Greenberg: [00:43:42] And along those lines, the only closing comment I would make is we've focused on the historical perspective of reporting, which was clinician recognition, state and local health departments, national CDC level surveillance. And, but there's one piece that we left off, which has I think completely changed in the last six years, and that's the role of families relative to reporting.



[00:44:08] And, you know, one of the things that's been great to see within our acute flaccid myelitis parents group and from the Siegel Rare Neuroimmune Association, is the integration now of patient advocacy groups with reporting whereas parents learn about potentially devastating, scary diagnoses, feeling empowered to go online, educate themselves, get reliable information from well-established and seasoned patient advocacy groups like these, and then be prompted to say, 'has your clinician reported this to state and local health departments?'

[00:44:48] I really can't overestimate the value of that process, especially around the rare diseases, because we may not penetrate the psyche of every clinician out there, ER docs, radiologists, neurologists around the countries. But families are an extremely powerful advocate for getting reliable, good, timely data in the hands of clinicians and epidemiologists to, to do appropriate surveillance. And so that's, that's been a shift that we didn't have 20 years ago when forming our epidemiology surveillance networks in the United States.

Rebecca Whitney: [00:45:25] Yes. Great point. Thank you.

Janell Routh: [00:45:28] I think this ties everything together with what Ben has seen about raising awareness amongst both families and clinicians and Emily saying that she's never upset to get a phone call from a clinician wanting to report a case.

[00:45:42] We learn from every single suspected AFM case that is reported, whether that case goes on to be confirmed at CDC or it's a probable or it is decided that this is not a case of AFM. Every single report gives us additional information about this uncommon illness. And so, you know, my, I guess, last words is to keep up the good work, really continue to encourage your clinicians to report in cases of AFM, because this is how we are going to learn the ins and outs of this illness, who is at risk for this illness, and how eventually we're going to develop treatment and prevention methods for this for this illness.

Rebecca Whitney: [00:46:27] Excellent. Thank you so much once again. I appreciate your time today.