

Seizing Life, episode 120
Comprehensive Epilepsy Centers: An Insider's Guide
Guest: Dr. Dave Clarke
(Transcript)

- Kelly Cervantes: Hi. I'm Kelly Cervantes and this is Seizing Life, a biweekly podcast produced by Cure Epilepsy. This week, I'm happy to welcome Dr. Dave Clarke, a pediatric epileptologist and chief of the comprehensive pediatric epilepsy program at Dell Children's Medical Center. Dr. Clarke is here today to give us an overview of comprehensive epilepsy centers, what they are, when to seek one out, and what they offer in terms of specialists and care. Dr. Clarke, thank you so much for joining us today. I would love to kick things off by finding out what drew you to neurology and specifically epilepsy.
- Dr. Dave Clarke: Sure. It's fantastic being here. Nice joining you. So, mine is a little bit more complex than most. So, I'm from Antigua, a small island in the Caribbean. Healthcare at the time wasn't optimal. I'm not sure if that was the driver, though. I really wanted to take care of children in some capacity and actually started out teaching, but then decided healthcare may be the optimal place to be. Based on persons that I were friends with with sickle cell and other conditions, I thought initially maybe hem/onc, but then realized quickly that I wanted to go into neurology. I had two very influential persons that did both epilepsy and sleep and that was my driver to go to epilepsy and sleep. Once I saw those squiggly lines of the EEG, I was sold. I couldn't turn back.
- Kelly Cervantes: I think it's fascinating that it's the squiggly lines of the EEG that make most of us go cross-eyed, that is what drew you in, I suppose. I wouldn't be surprised if you are someone who likes puzzles and decoding things.
- Dr. Dave Clarke: Yeah. I like that decoding. But even more important, it was the circuitry and within the field of epilepsy, quite often, you can do something to help and do something about, whereas when I was training, that wasn't always the case in other aspects of neurology.
- Kelly Cervantes: Now, I know that you are on the board of directors of NAEC, which stands for the National Association of Epilepsy Centers. Can you tell us what that organization does?
- Dr. Dave Clarke: Sure, sure. Do you mind if I go back a little bit and give a little history?
- Kelly Cervantes: Yeah. Absolutely.
- Dr. Dave Clarke: So, in about 1987, a collective of epileptologists thought, why not get together and define quality of care within the field and gauge different facilities and just raise the level of that care? So, for about, give or take, 10 years, there were about 30 to 50 centers. Then the Institute of Medicine decided that, you know what, accreditation may be needed for these centers to improve epilepsy care, and who better to do it than a collective of centers? So, now, the National Association of Epilepsy Centers, they're tasked with improving that care,

outlining what is required to help improve that care, and do more subspecialty care within the field of epilepsy.

Kelly Cervantes: So, I think some people may be familiar with the term Level 3, Level 4 epilepsy center. So, that is the NAEC is responsible for creating that system and then determining which medical centers, which hospitals fit into those different grades. Can you explain the difference between, I believe there's four epilepsy centers, so 1, 2, 3, and 4?

Dr. Dave Clarke: Sure, sure, sure. They're gauged towards where you enter the system with epilepsy, and epilepsy, that's two or more seizures and/or an epilepsy syndrome, or the risk of having epilepsy. So, the initial place that you're usually seen is either the primary care's office or the emergency room, and that would be a Level 1. They in turn tend to send you to perhaps a neurologist and that level of care would be more of a Level 2. Once you start getting into more subspecialty care, then you get to Level 3 and 4s. That's when you may have failed one or two medications or you can't better define what the epilepsy syndrome or epilepsy type is.

Kelly Cervantes: Excellent. Can you further define the difference, I guess, between a Level 3 and a Level 4 epilepsy center?

Dr. Dave Clarke: Sure. Excellent. Excellent. So, you have triage now, you've seen neurology, and now you want a higher level of care for the investigative studies to better define epilepsy syndrome, potentially doing other things like maybe the diet or further medications to advance that care. You'll get to a Level 3. Now, Level 3 may not always have the diet, but some do. Some have the diet and some have somewhat basic types of surgeries, taking out lesions and things like that. But once you want to get to a higher level, further investigative studies to determine is it a localization of focal epilepsy as it's now called, and whether you could potentially do epilepsy surgery, both palliative or definitive, or get more involved in the genetics of epilepsy and gauge more with in depth neuropsychological evaluations and things like that, that's when you get to that Level 4.

Kelly Cervantes: Should everyone try and get to a Level 4 center or are there certain people that you recommend aim for a Level 4?

Dr. Dave Clarke: Yeah. So, let's start from, I guess, what I'd describe as the ideal patient to get to a Level 4. If you have gone through two medications, based on prior studies, it's known that if you go to a third or put two medications together, the probability of seizure freedom, if the correct medicines are used, are often less than 5%. So, in those cases, it is suggested nationally that you have a surgical epilepsy workup. But even before getting to that, you have to go into what we described as a Phase 1 or epilepsy monitoring unit because as you would know, but maybe not everyone else would know, not everyone is amenable to that epilepsy surgery.

So, we don't want to just focus on that, say, 15 to 20% that you may help in that capacity. We really want to get to that larger population that are very difficult to treat, that we have to focus and better define what they may have vis-à-vis genetics or otherwise, whether they would be a great person for, say, the diet, any special medications that could target specific epilepsy syndromes. Then we define if they're not more generalized or more related to those syndromes, which ones could actually be helped significantly by epilepsy surgery?

Kelly Cervantes: So, we've talked a little bit about epilepsy centers, specifically Level 4 epilepsy centers, in previous podcast episodes. I know that at these epilepsy centers, it is more a team approach to patient care. Can you describe what that means and the different professionals that a patient and their family may come across when they enter a Level 4 epilepsy center?

Dr. Dave Clarke: I love these questions. It's definitely a multi-specialty deal you're walking into here. You don't treat the epilepsy or the seizure. You treat the individual who happens to have epilepsy. In order to treat that individual, because multiple circuits are involved with the seizures and something causes the seizures, there may be many other aspects of the brain that are affected. Therefore, you have to lay this foundation to look at all those aspects of care. You need neuropsychology because you want to see what that neurocognition is like. You need to definitely address the social determinants. You need a social worker.

That family or parent may not be able to navigate that care. A nurse navigator would be very helpful. An epilepsy surgeon is required if you need surgical care, a dietician, as a pediatric epileptologist, child life, us, the epileptologist. But there are many others, the nurse practitioners, the EEG technologists, and so forth, in that you want this comprehensive approach so that when that family comes in, you can really look at the overarching view of the person with epilepsy and take care of not only their needs, but the needs of other persons that may be affected within the family household.

Kelly Cervantes: Yeah. You brought up so many incredible points there. I want to highlight first that at these epilepsy centers, you're not just treating the seizures, you're treating the patient, and I think that that is so important because as so many of us know, epilepsy is far more than seizures. It impacts so many different parts of our life, and mental health, you talked about. I think so many times, I've heard so many patients talk about the comorbidities with mental health, but more specifically how difficult it can be to find a therapist or a mental health professional that understands epilepsy. At these epilepsy centers, you have a much better chance of finding those professionals. I also want to highlight how you were talking about that these epilepsy centers can help treat the family, and that is certainly something that my family experienced because, again, epilepsy doesn't just affect the patient. It affects the entire family.

You mentioned child life services. While those can be incredibly beneficial for the patient, I know for my family personally, my daughter was so intellectually impacted. There were some things that child life could do, but there wasn't as

much as they could for other children. But what they could do was help my son to understand the different procedures or equipment that my daughter was going through and that was an incredible help to me, to my son to make it all a little less scary. So, I do think that focus on the patient as a whole, that focus on the family as a unit is just so integral to helping manage and care for patients with epilepsy.

Brandon: Hi. This is Brandon from Cure Epilepsy. Have you or a loved one been recently diagnosed with epilepsy? Are you looking for more information about epilepsy and available treatment options? Go to cureepilepsy.org/for-patients to get resources and information about epilepsy. Now, back to Seizing Life.

Kelly Cervantes: It can be incredibly difficult to coordinate multiple doctors' and specialties' schedules. So, how does that happen within these centers to get all of this care to the patients?

Dr. Dave Clarke: So, fortunately, the National Association of Epilepsy Centers have outlined many of those essentials, and that's morphing. The new recommendations are actually going to come out later this year into next year. But that care coordination, as you suggest, is integral, and I'll just tell you the flow at our center and many centers. A neurologist and/or a parent or primary care physician reaches out and we have a clinical coordinator or epilepsy coordinator that reaches back to that person, find out the details, then they call a parent because they have to negotiate many things. They have to figure out when somebody has to take off work, or if it's a significant other, husband or wife, when they may have to do something differently. When can the child come in, per se, from school? When will they be in? When will they be out?

Because you have to look at quality of life also. Right? If somebody needs to come in urgently, getting that person in urgently. They define what they're going to go through within the hospital. They speak directly to the providers involved, vis-à-vis the nurse practitioners and epileptologists. Then once that person comes in and get monitored, once they're going from there to their next mean of management, be it surgery or otherwise, you need somebody to follow that track and, I shouldn't say hold the hand because it's sometime led by the parent, which is very appropriate. But follow exactly what needs to be done over time, getting to that end game.

Kelly Cervantes: So, what kind of tests and procedures can someone expect along the way?

Dr. Dave Clarke: Indeed. So, the very first thing is to define what's going on, and you do that within what's described as an epilepsy monitoring unit. Within that unit, the EEG is hooked up and the video is time locked to that EEG. Quite often, we may have to wean medications, not always, and seizures may occur. In realtime, we see the seizures, the video, we define where the seizures may be coming from with that EEG. But let's do a differentiator here. Let's just say we define that and we determine that seizures are coming from one hemisphere and/or one place within that hemisphere. Let's just say that person is going on to surgery. If

they're going on to surgery, the main thing is do no harm. So, you have to define function and you have to define where the seizures are coming from because you don't want to disrupt that function. You want to improve that function.

There are tests to define where the seizures are coming from. That's non-invasive. You're not going in at all. Then there are tests to define the function itself, and I'll just go through a few. There's what's called a SPECT scan, or [inaudible 00:14:56], in which you inject a isotope while they're having a seizure and then you inject it six to 24 hours after and you can subtract it and overlay it on the mri. There's a PET scan, which looks interictally, or in between seizures, and it identifies the area of lowest metabolic demand. There's a magnetoencephalogram, which measures micromagnetic fields, and I'll tell you why that's needed. When you're having a seizure in the brain, if it's coming from one area, in order for it to activate and go elsewhere and cause the clinical symptoms, it spreads, and the seizure itself is an exaggeration of that normal activity that you may do.

So, for instance, if I'm reaching out, I have control in picking up a pen, putting it down. If you're having a seizure, you may have more exaggerated jerks. If it's affecting the area of thinking, you may have forced thinking, etc. That current has to go through many conductants to get to the surface EEG. So, it takes a wide area of the brain to determine a discharge on top. If you're looking at magnetic fields, it doesn't do that. It's micromagnetic fields, so you can narrow that down to about one centimeter, sometimes two centimeters, pending where the seizure is coming from. So, that's localization and that's where the seizure is coming from.

But for function, functional MRI can overlay on a brain and determine where motor or sensory is or language or vision. The magnetoencephalogram can do that, or you can stimulate with a transcranial magnetic stimulator and actually cause twitches or movements just to determine function. You subtract those two and look at the brain in what's called a comprehensive surgical epilepsy meeting and within that meeting, a number of us, the neuropsychologists, all the persons that I spoke of earlier, we determine where it is, where function is, how to define it, and say, "Yes, you may be a candidate," or "No, you may not." That's just the surgical component.

Kelly Cervantes: Thank you so much. That's a lot. Keep going.

Dr. Dave Clarke: So, let's just say somebody has a slow spike in wave on EEG or have a specific semiology or characteristic of the EEG itself that matches an epilepsy syndrome. You may be able just by doing that to determine if it may be a limited epilepsy or something more prolonged. It may be a rolandic epilepsy and you know you may or may not have to treat, or you may determine it's a more epileptic encephalopathy or an epilepsy that impairs more your neurocognition. But some of those have a more targeted approach. So, then you want to touch base with your geneticist or epilepsy geneticist that we have here and elsewhere and they could better define what it is because now we have targeted medications.

So, for instance, if you have a condition like, say, Dravet syndrome, you know that certain medications may be helpful in that, based on pharmaceutical studies. Or if you have a GLUT1, just calling names, you don't have to know the details, the ketogenic diet may be the best medication for that. Right?

Then lastly, unfortunately, many folks may have both seizures and what we describe as not the best name, but non-epileptic paroxysms, or non-epilepsy spells. If you have that, you want to define one from the other because you don't want to ever overtreat again. Remember, your target is quality of life. Right? So, if we determine that some may be seizures and some may not be, you want to define one from the other. Or if we determine you may not have seizures, that outcome may be better, but epileptologists may not be best suited to treat that. You need a psychologist and/or psychiatrist. So, it's a very overarching approach, but the main thing is to define what's going on and define what may be the modes of management. I always say they shouldn't call it epilepsy, and I'm not the first one to say this. They should call it the epilepsies because there's so many different causes.

Kelly Cervantes: Dr. Clarke, we sort of touched on this a bit before, but I'm wondering if you can explain, we sort of talked about the different tests and the steps that someone may go to in terms of specifically their seizure monitoring and care. I wonder if you can talk a bit about what someone might expect for mental healthcare.

Dr. Dave Clarke: Yeah. Sure. Sure. So, when we say mental healthcare, we immediately tend to go to anxiety and depression, not always how it may affect the child or the family, which is very important. For the initial aspect of that care, we do screening and it's going to be suggested that others do similar screening for depression, anxiety, attentional problems, etc. But more formal testing usually happens with the neuropsychologist. The referral source for that, as you have alluded to before, is often very difficult, simply because they do not have that many psychiatrists and they may not have as many child psychiatrists.

But it's very important to have that referral source. Other aspects of that care involve the social worker, who quite often may do counseling, the psychologist quite often with biofeedback and/or counseling, and I would suggest other members of the epilepsy community. So, I think in total totality, mental health is as important as just about every other aspect of epilepsy. In the adult population, that's known. But in the pediatric population, we have to focus on it a lot more because I think we're doing a disservice to many of our kids not looking at that.

Kelly Cervantes: Yeah. I couldn't agree with you more. I can only imagine that there are people who are listening or watching to this who are thinking to themselves, wow, epilepsy 3 or 4 center sounds really amazing. How do I find out, A, where they are, and B, how do I get into one?

Dr. Dave Clarke: So, I'll tell you. We have more now. We have upwards of 250 centers. But you are correct. It's still very difficult. Fortunately, there's a National Association of

Epilepsy Center website that actually notify you where centers are within your state. Other organizations can lead the way also, American Epilepsy Society, the American Academy of Neurology. If your child has failed a number of medications or the syndrome has not been adequately diagnosed, there's no reason to wait for two medication failures to contact or engage with an epilepsy center. Most universities, major universities have centers like ours. But independent of those universities, many neurologists know of those centers. As with any other field in medicine, if you don't think as a family you're getting the care that your child deserves, you should be an advocate and you should push that physician, no matter where they are, including me, to advance that care or to reach out to someone else to improve that care.

Kelly Cervantes: Yeah. I'm a huge proponent of getting second, third, and fourth opinions and I think it's encouraging for people to hear from you, from an amazing doctor that you also encourage patients to get additional opinions and to branch out and see what other types of care are out there. So, we hear from people all the time about how it can take months to get in to see an epileptologist, specifically at a Level 3 or 4 epilepsy center. Do you have any tips or recommendations on how someone might be able to get in?

Dr. Dave Clarke: Yeah. No. I totally agree and I totally hear you. I think many of us are trying to bridge that gap and bridge that gap by engaging with primary care physicians and neurologists, but also using technology. Fortunately, the virtual world opened up quite a bit more with COVID and we are trying our best to not make that close again because that level of consultancy and engagement, not only with parents, families, children, but also with other physicians, have been quite helpful to better triage who should get into the center. Yeah.

I think when you engage with anyone within these centers, they should be able to determine urgency, but you also should push for, especially if your child is having quite a bit of seizures or comorbidities, the need for urgency [inaudible 00:24:57]. In saying all of that, we don't have enough centers and centers are not equally distributed throughout the United States. That's a given. We're trying to mitigate that by educating primary care providers, and you notice I didn't say physician necessarily, but primary care providers, be it nurse practitioners, PAs, nurse educators, etc, as to what to do, when to refer, how to engage with families and their children.

Kelly Cervantes: Well, and sort of what you're touching on here sort of perfectly leads into another area of interest for you, which is getting epilepsy care to underserved communities. Certainly, telehealth has helped with that, but I wonder if you can speak to that and the various disparities that we are seeing in communities who are low income or who are hundreds of miles away from a proper epilepsy center.

Dr. Dave Clarke: No, no. Surely, I appreciate you asking that question because it's something that's near and dear, but very appropriately asked. So, just taking a step back, there are deficits with everyone with epilepsy, deficits in care with everyone. It's

estimated that probably time from diagnosis to being seen by a neurologist sometimes takes as long as three years. That should take about a month.

Kelly Cervantes: Yeah.

Dr. Dave Clarke: Right?

Kelly Cervantes: Yeah.

Dr. Dave Clarke: It's estimated that sometimes, time to surgery takes longer than 10 years, or surgical workup. That should take one to three years. There's a huge deficit in surgeries performed. Persons getting genetic testing, there's a huge deficit. Then you layer on top of that if you're not close to a region that could provide that. How do you provide transport if you're uninsured or underinsured? Unfortunately, there's still concerns related to language and communication, cultural concerns, racial sensitivities, etc., etc. So, the question is how do you bridge that gap? I think one start is to better define social determinants. But the other thing, again, is to use technology to try and mitigate some of those concerns. That's what not only myself, but others have been doing for a while, but fortunately, that's picking up speed as we become more and more aware of what the concerns are.

Kelly Cervantes: So, through technology, you're talking about the telehealth communication. But I also imagine that just education is a huge part of that, helping people to understand that they are having a seizure. Some people may not even know that what they are experiencing or what their child is experiencing is even a seizure.

Dr. Dave Clarke: Totally, totally agree at all levels. If they could potentially put on a television or YouTube descriptors of different seizure type for families, that would be great for me. Right. Within the field of asthma, most persons would know what it looks like, what it sounds like, and when to seek care. For epilepsy, I think it should be the same. Right? For primary care physicians, I agree, neurologists also. But beyond just clinical care, when do we start screening? That's a project that myself and a colleague, Kristina Julich, and others are doing. We need to start trying to screen for, say, genetic conditions with persons with epilepsy.

How can I screen if someone lives two, three, four, five, eight hours away? How about neuropsychological problems? Just suppose you have had two seizures and you come in, it's a circuitry problem. Suppose you can screen for subtleties. How much will you impact that child if you immediately start taking care of, it may not be medicine, but abilities to help them focus better? What are the ramifications of that three, four, five, six, seven, eight years down the road? Berg and others have shown this is significant. So, I think there's more than enough for persons to do to mitigate that problem, but there's definitely an access problem and we're trying to address it.

Kelly Cervantes: So, I wonder, someone who is listening to this podcast, what steps do you recommend that they take to get to an epilepsy Level 3 or Level 4 center?

Dr. Dave Clarke: If they have a neurologist, I suggest that they speak to that neurologist about what's actively going on now, their concerns, and they need to get to that Level 3 or Level 4 center. They could also speak to a primary care physician. But if there are hiccups, I don't think anyone would argue that they should try and reach out to that center themselves by going on the website. Now, of course, you want to engage with your physician because that's the person that ultimately is going to be somewhat of a band leader for you to advance that care. But as both of us alluded to earlier, you are the main advocate for your child or for your significant other. Therefore, you should never be ashamed of advocating for the care of that person.

Kelly Cervantes: 100%. One of the best pieces of advice that I received right after my daughter was diagnosed was have the fight and not go toe to toe, but advocate, and when you feel strongly about something, ask the questions and make the phone calls and do whatever you need to do because no one is going to advocate for your loved one as well or as hard as you will. Dr. Clarke, thank you so, so much for sharing all of your knowledge and insights with us today. This has been so incredibly informative and I imagine an interview that many people will bookmark and come back to. Thank you.

Dr. Dave Clarke: Thank you. I hope it was very helpful. A lot of my learning and my ongoing learning are from families and kids, especially teenagers. They tend not to have much of a frontal lobe. So, they tell me as it is, and it's been very helpful over time. But also, some of the strongest advocates I've seen are primary care physicians. So, please don't neglect informing your primary care physician. They're the ones that tend to see you and know you. So, please be inclusive of them, and I'll sort of leave it there.

Kelly Cervantes: Oh, thank you so much.

Dr. Dave Clarke: Indeed. Thanks again, guys. Appreciate it.

Kelly Cervantes: Thank you, Dr. Clarke, for sharing your expertise and insights and advice on accessing care at comprehensive epilepsy centers. For 25 years, Cure Epilepsy has sought to push science forward by funding cutting edge, patient-focused epilepsy research. In that time, significant progress has been made in understanding and treating epilepsy, but our goal is finding a cure. If you would like to help us achieve that goal, please visit cureepilepsy.org/donate. Cure Epilepsy, inspiring hope and delivering impact. Thank you.

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