

Seizing Life, episode 96
Determination and New Technology Lead to Successful Epilepsy Surgery
Guest: Kate Neale Cooper
(Transcript)

Kelly Cervantes:	00:00	Hi, I'm Kelly Cervantes and this is Seizing Life, a biweekly podcast produced by CURE Epilepsy.
Kelly Cervantes:	00:18	Today, I'm happy to welcome epilepsy advocate and Cure Epilepsy champion, Kate Neale Cooper to the podcast. Kate's daughter, Virginia, was diagnosed with epilepsy at 17 months, beginning a 16-year treatment journey that culminated in brain surgery in December 2020. Kate is here to share details of their journey and tell us how a recent advance in diagnostic testing helped determine that Virginia was a candidate for surgery.
Kelly Cervantes:	00:47	Kate, thank you so much for joining us today. This is a full circle moment for me personally, as you were one of the very first epilepsy mamas that I was ever introduced to, so I'm so honored to have you on and to share your and Virginia's story. So let's just get right into it. How did epilepsy enter your and your daughter Virginia's life?
Kate Neale Cooper:	01:15	Gosh, it happened really fast and completely out of the blue. I guess that's probably the way it happens for a lot of people. Virginia was 17 months old. One day in August, it was 2004 and we were sitting in the family room. She was rocking on a rocking horse and then just stopped suddenly and made this very funny face that looked to me like a vomit reflex at first. I thought she was going to be sick, so I scooped her up and ran to the bathroom with her and then nothing happened, but she went on to do that a few more times that same day. And as I laid awake at night thinking about it, I thought that doesn't make sense that that would happen more than a couple of times.
Kate Neale Cooper:	01:56	So I was telling my husband about it the next morning. He was standing nearby and holding her. And while I was telling him what I had seen, she did it again. So Virginia is a tiny little person. She's really small. And the doctors were a little worried about that. I wasn't because I'm not a big person. And so I used that as an excuse. They were always saying, "Oh, bring her in to get weighed, bring her in to get weighed. We want to track her progress."
Kate Neale Cooper:	02:19	So it was a Saturday morning and I thought I'll just go in and get her weighed. And I'll mention that she's doing this funny thing. And as soon as I got to the pediatrician's office, she did it again. And I yelled and God bless our doctors, they came running, not knowing what was happening and they witnessed it. So very quickly, a diagnosis was set in motion because we went straight

from the pediatrician's office to the ER. In the ER, she had a seizure right in front of an attending. They admitted her. And when the neurologist came to the room, she had one again. So as scary as it was, the fact that she just started clustering proved really helpful because we very quickly knew, okay, these were seizures and she needs to be admitted and evaluated. So it was a really fast diagnosis.

Kelly Cervantes: 03:04

Wow. I mean, it sounds ridiculous, but I mean very convenient for her to have these seizures at opportunistic moments when the people who needed to see them were in the room. I don't know how many people go through 48 hour EEG emissions and never have a seizure when you need to have them. What did you know about epilepsy at the time of her diagnosis?

Kate Neale Cooper: 03:30

Yeah. I fought a lot about that since then. And I think honestly, I knew nothing, which, in a way, was a real gift because for years there's been a real stigma attached to epilepsy, a lot of confusion around it. And I think the fact that I went into it a blank slate actually worked in my favor. We were told that 75% of kids outgrow it. We were never able, in that initial evaluation, that initial hospital stay was about five days, CAT scans, MRIs, the basic workup, we were told that it was idiopathic. It had no known cause. And we felt like in that moment, anyway, like we had won the lottery. There was no brain tumor. There was no brain bleed. There were none of these nefarious things that can sometimes cause seizures. So naively, we thought, yeah, she'll outgrow it, maybe it'll never happen again. She's on this medicine now. So we left feeling quite optimistic with this 17-month-old, but it didn't pan out that way at all.

Kelly Cervantes: 04:26

So what was her treatment journey like since, unfortunately, she wasn't part of that two-thirds of epilepsy patients that do find relief from medications?

Kate Neale Cooper: 04:40

Right, right. So she fell into that one-third that nothing was working for. And it was a really long journey overall. It was 16 years and it included a little bit of everything. I mean, we tried probably close to a dozen drugs, all the names everybody knows, so Klonopin, Topomax, Depakote, Keppra, Lamictil, everything. We never got full seizure control with that. We tried the ketogenic diet eventually, by then she was in middle school. I wish we had tried it earlier, actually, but you make the best decisions you can in the moment with the best information you have, but that wasn't effective either.

Kate Neale Cooper: 05:23

Actually, before we tried the ketogenic diet, I went a little out of order there, when she was in the third grade, so about nine, her

doctor that we were seeing suggested that maybe she would be a surgery for candidate. He explained that these medicines all are chemically very similar. And once you fail two or three of them, the chances of another one working are not very good. And so we started that surgery conversation and we had sought second opinions and third opinions and at different stages of her life, gone to different doctors, depending on what worked best for us logistically. And there were a number of factors.

Kate Neale Cooper: 05:56

So by the time she was in third grade, she was seeing a doctor about an hour away and he suggested we go to Washington DC to talk to a neurosurgeon there. And that started about a year and a half long journey of a surgical evaluation. So we pursued all the different specialists they referred us to CAT scan, PET scan, SPECT scan. So we did a little bit of everything. And again, Virginia was incredibly predictable. We knew exactly how to make her have a seizure. We could reliably take her off her medication, sleep deprive her a little and then in the moment of the imaging, she always had a seizure, in the MRI machine, during the PET scan, whatever it was. But unfortunately, they still could not see the focal point. So we gave up there for a little while on the surgery front and just went back to medication.

Kelly Cervantes: 06:46

How many seizures was Virginia having? What was the epilepsy's impact on her day-to-day life as a young child?

Kate Neale Cooper: 06:56

As we know, epilepsy can be a really invisible disease. Unless you saw Virginia have a seizure, you might not know that she had epilepsy, but we saw it in her ability to concentrate and focus and stay on task. She'd compensated for it very well. So she very rarely had a seizure. And then that was it. They tended to happen 12 at a time for days. At its worst, she was having 40 to 60 a day. That was when she was four. And that lasted for about three months.

Kate Neale Cooper: 07:32

One of the biggest challenges with Virginia's seizures is that they were often nocturnal. So what that meant for her and for us was that sleep was interrupted. So she was never getting a good night's sleep. And as we all know, sleep is incredibly important to young children as they're growing and learning and developing. So it affected her concentration. It affected her academics. It affected her ability to just function. Imagine a world where you're woken up three or four times a night. And then, of course, they're all the risks of nocturnal seizures as well. So at the end of her epilepsy journey at the age of 17, she was having about 10 a week and they were happening almost exclusively from three or four in the morning on and really, interrupting that all important teenage sleep.

Kelly Cervantes:	08:19	So how did you eventually arrive at surgery as an option? If you do this workup when she's eight, they say, "I'm so sorry. We can't localize where this is occurring from. She's failing medications, failing the ketogenic diet." And then you land back on surgery?
Kate Neale Cooper:	08:40	So in the summer of Virginia's junior year, a doctor suggested we try a high density EEG. A regular EEG has about 26 or 28 leads directly on the scalp of the head, so it's measuring brain activity through the hair, through the scalp, through the skull. A high density EEG has hundreds of leads on it, so you're getting a much clearer picture and a better picture of what's happening. So we attempted that and it was unsuccessful. And then we went back to talking about surgery, to talking about a diagnostic surgery. And that doctor proposed what is called a stereo EEG. So it's another form of EEG, but rather than looking at everything through the scalp and through the skull, they actually go into the brain. So during surgery, they drill holes in the brain and they insert electrode depths.
Kate Neale Cooper:	09:34	So there's an electrode like this, and it has little sensors all along the depth of it, so they're collecting a lot more data and they're getting a lot closer to the actual seizure activity. So ended up doing that test in her junior year.
Kelly Cervantes:	09:50	And did that help you find the localization?
Kate Neale Cooper:	09:55	Yeah. It helped us figure out where it wasn't. So again, the treatment journey was really complicated. So this is February 2020, Virginia goes in for a stereo EEG. They drill 15 holes in her skull and into her brain. They stick these right into the soft tissue. They put these depth electrodes. It was a seven and a half hour surgery. Yeah, it was pretty intense. Then she went up to the epilepsy monitoring unit. So this is a familiar journey for me and for lots of people who are a caregiver. You go into the EMU, you take them off their medication and you let them have seizures.
Kate Neale Cooper:	10:35	With Virginia, again, very predictable. We took her off her medication as soon as she was stable after the surgery and all hell breaks loose. She has a bunch of seizures and that's exactly what we wanted. It's really a fact finding mission, right? You're collecting as much data as you possibly can. It's a second surgery to go in and have the leads taken out. The doctors tell us they'll be in touch in a few weeks to report what their findings are. Her surgery was February 6th, 2020. We all know what happened the next month. The whole world shut down with COVID and the hospital went dark. We didn't hear

anything, but while we were in the hospital, they weren't super encouraging. They weren't very hopeful. They had been unable to look at one entire part of her scalp or one entire part of her brain, rather, because there were too many veins nearby and so they wondered if they were missing something.

- Kate Neale Cooper: 11:29 So when they finally came back, they basically said that she wasn't a surgery candidate, not for a resection, they can't remove part of her brain, but they could do a surgery and implant a device. And they were suggesting deep brain stimulation, which is a great option for a lot of people. It could reduce the number of seizures, decrease the risk of death. Virginia had a lot of nocturnal seizures, so the risk of death is higher with people like that. And it would reduce the risk of forgetting her medicine if she were off at college and she forgot her medicine, the DBS would be this backup system for her. I was not convinced that was our best option. If this was the end of the road, I wanted to hear from somebody else that it was the end of the road. I was going to get a second opinion, which was really like an 11th opinion, but a second opinion on this particular aspect.
- Brandon: 12:23 Hi, this is Brandon from CURE Epilepsy. Did you know that 30% of those diagnosed with epilepsy do not respond to current medications? That is why for over 20 years Cure Epilepsy has been dedicated to funding patient-focused research to find a cure for epilepsy. Learn more about our mission and our research by visiting cureepilepsy.org. Now back to Seizing Life.
- Kelly Cervantes: 12:47 So you have your mommy gut instinct here that there is something being left on the table with this surgery evaluation. What was your next step?
- Kate Neale Cooper: 13:01 So while I was still waiting to hear back on the results from the first SEEG, the first stereo EEG, I actually started doing some research on my own. And I actually think, Kelly, I thought about this today. I actually think I ended up following Scott Perry, Dr. Perry, at Cook Children's because you follow him. I think it was one of the Twitter algorithms where you might also want to follow the notorious EEG. And of course, I was intrigued because you have to love that Twitter handle, right?
- Kelly Cervantes: 13:31 It's the best.
- Kate Neale Cooper: 13:32 Somebody with a sense of humor in neurology is just such a great thing. So I was following Dr. Perry on Twitter, and I was so impressed by his humility and his interest in problem-solving and tough cases. And he just spoke about epilepsy in a really

different way. So I eventually reached out to his office and I said, "I'd love a second opinion on our daughter. We're awaiting the results of the SEEG." And I dealt with Dr. Perry's clinical coordinator to arrange a visit for another evaluation. And then we flew to Texas during that first COVID summer, flew down to Texas to talk to them about what else we should be considering, what else we should be looking at. And they had some ideas about tests we had never done and it was a game changer.

Kelly Cervantes: 14:21

So what tests was it that they suggested?

Kate Neale Cooper: 14:24

What ended up being pivotal for us during that visit was a study that Virginia was enrolled in that combined an MEG with a high density EEG. We already talked about that high density EEG, where they're doing a scalp EEG, but it has hundreds of leads on it instead of the typical 26. Well, she did that during an MEG, which is a really sophisticated imaging test. It's this big machine that looks like one of those old fashioned hood hair dryers on steroids. It's a cross between one of those hair dryers and a personal rocket ship. It's really cool looking. So she went into that machine. Again, we've sleep deprived her, we've taken her off her medication and they are looking for electrical activity in the brain.

Kate Neale Cooper: 15:11

And what they do is they take the results of the MEG and the results from the high density EEG. They map that data on a model of her brain that they've built from MRIs that they've done. And they used this for pre-surgery planning. So when they did that and took all that data, they could identify these dye poles, these areas of electrical activity that confirmed their hunch about where the seizures were coming from. So basically they had found it. It was like X marks the spot when you put all this data on the brain model.

Kate Neale Cooper: 15:47

So they were really confident that they had it, but then they said, "We're not so confident that we can do surgery yet. We have to actually really pinpoint it." Because you can imagine there are parts of the brain you don't want to get near with a laser or a knife or whatever, so they have to really, really, really narrow it down to the tiniest possible point. The good news was we'd found, great. The bad news was we were going to have to repeat that stereo EEG. We're going to have to redo that diagnostic surgery. So they told us this in September 2020, and we flew down there again in November 2020 to repeat that stereo EEG for a second time.

Kelly Cervantes: 16:35

Wow. So this is the one where there are drilling holes in her skull?

Kate Neale Cooper:	16:41	Exactly.
Kelly Cervantes:	16:42	And you're walking into doing that again. Wow. I mean, that's a commitment to make.
Kate Neale Cooper:	16:47	We're walking into doing it again, but the good news is, again, we know where it's not. We've already eliminated those 15 points where they drill holes before. So we're looking at a much smaller space and we have the data from the MEG and the high density EEG and we've localized it, not enough for surgery, but enough that the SEEG is going to be much more contained. So this time instead of 15 holes, we're drilling seven and we're putting seven leads into her brain. And the whole surgery was just very smooth. It was about two and a half hours.
Kelly Cervantes:	17:21	And how was Virginia during all of this? I mean, that's a lot for anyone to go through, let alone and already erratically emotional teenager.
Kate Neale Cooper:	17:32	Yeah. It was incredibly hard. And to your point, signing up for it a second time and knowing how awful it could be and uncomfortable. So as you can imagine, if you've got probes in your brain, you can't get up and walk around. This is not a normal EMU visit. You are stuck in bed and you have to be extremely careful, but we had a better idea of what it would be like. We knew what to expect. Virginia would be the first to tell you that the staff was amazing. And the way they explained things to her was really good. It wasn't condescending, but it was in plain English. So I think she had a better rapport with everybody. And the one blessing of COVID was that a lot of people were missing school for various reasons. A lot of people were doing remote school. So for her to be doing remote school, she didn't stand out in any way. And that was a bit of a blessing as well.
Kelly Cervantes:	18:21	So you do the SEEG, you get this information and they're like, voila. We know where these are occurring from 16 years later.
Kate Neale Cooper:	18:36	Exactly, exactly what happened. Before they even took the probes out, because remember it's a second surgery to go in and take the probes out, so before they even did that, they came into the room and said, "We want to try one thing really quickly." And I was hearing some chatter in the hallways and I knew something big was happening. And so they actually attached wires to the seven leads. They were in her brain and they explained that they were going to start stimulating them and see which one caused a seizure to confirm their hypothesis. And so they started with the leads that were farthest from the

spot that they thought the seizures were coming from, farthest from the focal point. And they said, as we get closer and closer, she's going to have a seizure. And I said, "Yeah, I've seen about 17,000 of them. I'm prepared."

Kate Neale Cooper: 19:23

But Virginia was warned and sure enough, they hit that last one and she had a seizure and they said, "We know exactly where they're coming from." And the even bigger news was that they could do a laser ablation. So what we learned was that the spot that they were coming from, actually two very small spots, were small enough, discreet enough and accessible enough that we could do a laser ablation, which means that we're burning away these two tiny spots with a laser, rather than having to open her scalp, open her skull and actually go in and resect, which is much more invasive. So we knew it was going to be a simpler surgery with less downtime. It was just fabulous news. And she hadn't even gone in for the surgery to take the leads out yet. They were so quick in their analysis. It was amazing.

Kelly Cervantes: 20:11

Wow. That's amazing. So how long is it then you get this information, they know exactly where the seizures are originating from, they know exactly how they're going to do the surgery. How long from that point until when the surgery occurred?

Kate Neale Cooper: 20:30

So this is where, again, it was really interesting because of COVID. They told us they could do it in about three weeks. We hunkered down, tried to limit our exposure as much as possible and went back into the hospital just about two and a half weeks later to perform the actual surgery. So it all happened very quickly once they were able to localize it.

Kelly Cervantes: 20:50

So you go in and they conduct the surgery, the laser ablation versus having to open up her skull, sounds like it's a little easier to swallow.

Kate Neale Cooper: 21:04

Oh, it certainly is. It certainly is. And as you know, I mean, as an epilepsy caregiver, you've lived through so much. When someone tells you there's brain surgery does not have the same connotation for me that it does for other people. I'm like, bring it on. Yeah, great. Let's do it. It was such a joyous thing in our household, rather than a scary thing. And a laser ablation is super fascinating. So it actually was less invasive than the diagnostic surgeries, than the SEEGs that she had. So for this laser ablation, they can get within one millimeter of the problem area. I mean, that's how small the laser. So you're talking about like that grain of sand. It's so incredibly precise.

Kate Neale Cooper:	21:47	So yeah, all they do is they drill two tiny little, in her case, they drill two tiny little holes right on her hairline. And so they drill these two tiny little holes and it's an MRI-guided surgery. So she's in a special suite under an MRI while the surgeons are behind another door operating this robot that is doing the surgery. And so that they're doing it guided by the MRI so that they can tell exactly where they are.
Kate Neale Cooper:	22:16	Again, it is brain surgery and there are some eloquent part of the brain that we don't want to touch. We want to stay as controlled as we possibly can. So they drill these two tiny holes. They put these fiber optic cables with lasers at the end in them. And then they slowly pull these cables back out and the laser burns away the distillation in her brain. So that part of it where they're actually burning away part of her brain is only 20 minutes, but the surgery as a whole is about four hours from the time you say goodbye to your child to the time you see them again. There's a lot of prep work. There's a lot of cleanup afterwards, but the surgery itself is just 20 minutes and she came out with two tiny little stitches. I mean, we've gotten worse injuries at a birthday party, just two tiny little stitches right in the part of her hair. And that was it.
Kelly Cervantes:	23:08	Wow. That's amazing. And when did you start to notice the effects of the surgery?
Kate Neale Cooper:	23:16	Right away. I mean, Virginia had seizures every single day. So when she woke up and didn't have any seizures all day and then woke up the next day and hadn't had any seizures. We were hopeful. We've had false hope before. It's not that she'd never gone a day without seizures, but at that point in time in her particular seizure pattern, that was incredibly encouraging. So she had surgery on December 2nd. She was discharged from the hospital on December 3rd and we flew home on December 4th. And that was it.
Kelly Cervantes:	23:49	No more seizures?
Kate Neale Cooper:	23:51	No more seizures.
Kelly Cervantes:	23:52	She has been seizure free since December 2020.
Kate Neale Cooper:	23:57	Yep.
Kelly Cervantes:	23:58	How has that affected her life? How has that affected your life?

- Kate Neale Cooper: 24:04 It's really, really hard to talk about. I mean, both because it's a qualitative improvement and a quantitative improvement, right? One little anecdote to give you a sense of something that I think is truly amazing. So Virginia had this surgery during her senior year of high school. She is looking at colleges and she's taking her standardized testing. She's writing essay applications. In fact, I'll never forget when she was getting her second SEEG that morning in Texas, she was just looking at her phone while she was waiting for her turn to be wheeled back. And that's when she got her first college acceptance while she was laying in bed and everybody in the OR theater just erupted and was so happy for her. And she had taken her ACT a couple of times before her brain surgery. She actually wanted to apply to a particular school in Canada, where Americans have to have a minimum score to even be allowed to apply. And she was just short of that minimum score.
- Kate Neale Cooper: 24:59 And a week after we got home from brain surgery, she said, "Oh, I, can you wake me up early? Be sure I get up. I have the ACT tomorrow morning." And I said, "Sweetie, you had brain surgery a week ago and you've already taken the ACT. I thought we were done." And she said, "No, no, no. Remember I want to get that score to go to McGill. I want to take it again." And Kelly, her score went up four points, which on the ACT, it's an exponential scale. So it's huge. And I immediately told Dr. Perry and he said, "Yeah, she was not only having the seizures we saw, she was probably having little tiny seizures all the time. And her brain was being interrupted all the time."
- Kate Neale Cooper: 25:41 So her ability to focus and to remember got so much better immediately. And most importantly, it meant she could leave home and go to college, which is what she always wanted to do. So she'll be a freshman this year in college and she's moving out on her own. And I don't wake up in a panic, wondering if she's taken her medicine.
- Kelly Cervantes: 26:03 Are there other ways that her seizure freedom has affected her life and her future?
- Kate Neale Cooper: 26:11 Yeah, absolutely. One of the most obvious ones is driving. Virginia's not driving yet, but she's working towards that. And for a lot of people, having seizures means that your livelihood is really compromised. So she'll be able to get a driver's license post-surgery, which is really great. That opens up all sorts of opportunities, professionally, socially, the whole thing. And then, socially, she has said, "I'm not the girl with epilepsy anymore." She doesn't have to explain that to new friends. She doesn't have to worry about sleepovers. If you think about

college, what is it like to live with a roommate who has seizures? People have done it, but it's very difficult. So going forward in friendships and romantic relationships, not having to explain seizures and not having to worry about them when you don't know someone very well is a huge benefit for her. She feels like a new person from that perspective.

Kelly Cervantes: 27:04

I can only imagine. And what advice do you have for other parents out there who are still fighting to achieve some sort of seizure control?

Kate Neale Cooper: 27:16

Gosh, that's a big one. So I think one of the most important things is finding a really great relationship with your epileptologist, neurologist, neurosurgeon, whoever is on your team. And I really think it's important to acknowledge that that relationship can change over time. So the person that Virginia saw for years as a very small child was great. And we had a great relationship with him, but as she got older, it was harder to leave school. It was harder to explain absences to her friends. It became time to go to someone maybe a little bit closer or someone with a different approach. So sometimes the second opinion is for medical reasons. And sometimes it's for logistical reasons. This is a long journey for a lot of people and every doctor you're seeing would do the same thing for their kid, would get a second, third, fourth opinion. So I really encourage people to do that whenever they can, especially when they're facing a really big decision like surgery or no surgery.

Kate Neale Cooper: 28:17

The other thing I would say, I adamantly believe in a full surgery workup as soon as you can do it, as soon as you see that that second medication isn't giving you complete seizure control, start the surgery workup. That doesn't mean you're committed to having surgery. It means you're on a fact finding mission and you're getting a lot more information. And when you do that, you have to remember that's where that second, third, fourth opinion comes in because not every medical center is created equal. So you want to be at the places with the best equipment, the best technology, the best neurosurgeons, which are different from your neurologist and epileptologist. Start that workup sooner rather than later.

Kelly Cervantes: 28:58

And I think your experience also speaks to the fact that technology is moving forward and you had this workup done when she was eight and then it took another nine years before that you were able to find the surgical option for her and technology had advanced. I mean, you spoke about the MEG. MEG machines are really new. They're just starting. There's only a couple handfuls of them throughout the country. So I think

that that's an important piece too, is you go and you do that surgery workup or you do the test, be it genetic or the scans, but then you do them again a few years later because technology advances and maybe they can find something new this time.

- Kate Neale Cooper: 29:53 Agreed. And honestly, even the technology might be there, but they might use it differently. The MEG has been around for a long time for, well, relatively long time, for research purposes, but people weren't using them clinically. And to your point, there aren't that many of them. So yeah, I think that's a really hopeful message. Technology is moving so fast, whether it's the actual machines or if you think about the cloud and big data. These tests produce a tremendous amount of data. And now with the cloud, they can look at huge data sets much more quickly. They can do so much more. So I think it's a real message of hope. And to your point, repeat the test because the test is not the same year to year. Your kid is not the same year to year. Repeat, repeat, repeat. It's exhausting, but you got to do it.
- Kelly Cervantes: 30:39 You're absolutely right. You are 100% right. Kate, thank you so, so much for sharing your and Virginia's story with us today, for educating us on what a brain workup looks like, a surgery workup looks like from the patient care giver standpoint. And we're just so excited that Virginia is doing so well with her epilepsy today. And we wish you the best of luck in the future. Thank you so, so very much. And please give Virginia our best.
- Kate Neale Cooper: 31:14 I will. Thanks, Kelly. Thanks for everything you and your family do. We really appreciate it.
- Kelly Cervantes: 31:21 Thank you, Kate, for sharing your daughter's treatment journey and for all your advocacy for the epilepsy community. As Kate mentioned, Virginia was one of the one-third of people with epilepsy who do not respond to current treatments. That's more than a million people in the United States alone who are unable to attain seizure control through medication. For these people and their families, the best hope is research. That is why CURE Epilepsy is dedicated to supporting patient-focused research to find new therapies and cures for epilepsy. We hope you'll join us in our mission by visiting cureepilepsy.org/donate. Through research, there is hope. Thank you.
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