Seizing Life, episode 69
Infantile Spasms: Awareness, Observation, and Intervention
Guest: Lissy Griffin

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 Lissy Griffin to the podcast to talk about a very important subject. When her six-month-old daughter, Madison, began exhibiting strange but subtle involuntary movements, Lissy acted quickly to get the opinion of medical professionals. The result was a diagnosis of infantile spasms, a rare, but potentially devastating neurological condition. Thankfully, Lissy's quick action and insistent approach with doctors resulted in early intervention and may have been a key factor in her daughter's outcome. Lissy is here today to share her story and raise awareness about infantile spasms.
Kelly Cervantes:	00:53	If you are a new parent or planning to become a parent, or if you know new parents, I urge you to continue listening to this episode.
Kelly Cervantes:	01:02	Lissy, thank you so much for joining us today to chat all things, infantile spasms, and specifically about your daughter Madison. I'm wondering at what point or what was the first initial sign that you thought something was a little off?
Lissy Griffin:	01:21	It was actually her teacher from school when I came to pick her up that had sat me down and said, "Madison did something really weird today. I had her on the changing table and she kind of had her arms out, like she was catching herself falling, but she did it a few times." And she was the one who actually said seizure. She said, "I don't know if that's what it was," but just hearing that concerned me. So we brought her home and I kept an eye on her and we didn't see anything. And then the following morning, I actually saw it myself and started videotaping it and immediately called the pediatrician and took her there.
Kelly Cervantes:	01:57	Awesome job, by the way, on filming those seizures. I think that it's such an important and critical step because our kids never have seizures when we need them to be in the hospital or in the pediatrician's office. So kudos to you for filming that so you could show the pediatrician. Then what did the pediatrician say to you?
Lissy Griffin:	02:17	The pediatrician looked at the videos and to be fair in the videos, Madison was sitting in a seat. She wasn't laying down and it wasn't an obvious, but me looking at it, I knew as her mom, I was like, "That's weird. Did you see that?" She said, "Oh,

it could be a startle reflex or acid reflux. Keep an eye on it for a month and take her to a neurologist in about a month if she's still doing that." And when I left, my mom said, "Don't you feel so much better? They said it wasn't anything." I said, "They didn't tell me what it was. I don't feel better." I didn't feel good about that conversation because it wasn't this is what it is and everything's fine. We left with it an unknown, which definitely was concerning.

Kelly Cervantes: 03:02 Absolutely. And had Madison had any other developmental delays or medical problems prior to these first sort of startled reflux looking spasms?

Lissy Griffin: 03:18 No. Madison was developmentally on track. We didn't have anything when I was pregnant or during birth, nothing that made us believe up until that point that anything would be wrong.

Kelly Cervantes: 03:32 So you still have this sort of pit in your stomach after seeing the pediatrician. What motivated you to get a second opinion?

Lissy Griffin: 03:42 We definitely noticed throughout that next day. So it was Thursday that our teacher sent me down. Friday, took her to the pediatrician. And then it was almost instantaneous that you started to really see them happening more frequently and she started to get upset, which then upset me. The first few that she did, she would have one and go back to playing. The second few and third, fourth, fifth that it happened, it was happening in these longer clusters and she was started to cry and get upset and that really concerned me. So I started to reach out and Google and YouTube everything to try and figure out what it was. And after a little bit of my own research, I realized that we probably just should take her to the hospital.

Kelly Cervantes: 04:29 Yeah. I call it a Google dumpster dive and I feel like it is a rite of passage for so many of us in this world. Dr. Google is not always right, but certainly pointed you in the right direction this time. So you take her to the emergency room and what did they tell you there?

Lissy Griffin: 04:52 When we went, we're very, very lucky that we have a children's hospital within driving distance of us. So we took her to, we call it CHOP, Children's Hospital of Philadelphia. And I actually went in and I said, "My daughter has infantile spasms." And they kind of were like, "Sure, she does." I'm showing them videos and she actually started to have a cluster while we were in the emergency department. Unfortunately, the person we were seeing kind of wasn't seeing what she was doing. They were

		like, "Oh, can you show me the video again?" I was like, "She's doing it right now. This is it." And then they brought somebody else in who was more like the head of the department. And she said, "Pick up your daughter. We're going to take you right upstairs." And they immediately set us up with a video and overnight 24-hour EEG.
Kelly Cervantes:	05:41	And then at what point did you get the official infantile spasms diagnosis?
Lissy Griffin:	05:46	We spent the night at CHOP and they give you this little button. And every time they say, "If you see her doing something, press the button." And it was the next morning we woke up and they were doing their rotations. And the neurologist came in and she sat us down and said, "Your daughter has infantile spasms." Which for a moment was almost a relief to me of I followed my gut and I felt good about the fact that I did that. It was definitely harder for my husband, who I think up till this point was under the impression it was probably nothing. And the first thing they actually said was don't Google anymore because infantile spasms, it's such an umbrella under epilepsy, which is in an even bigger umbrella, that they said, "You're going to Google it and it's going to tell you a wide range of what her future looks like. And for now, that's not very helpful. Let's start figuring out the next steps."
Lissy Griffin:	06:48	And Madison had infantile spasms with hypsarrhythmia. So they also then educated us a bit on that and said, "The next steps are to try and find a cause." So we went forth the next day and got an MRI and a spinal tap done. They said that they couldn't figure out a cause. And so it was considered cryptogenic and that they would proceed with the most aggressive treatment of ACTH, which is a steroid.
Kelly Cervantes:	07:18	I want to unpack.
Lissy Griffin:	07:19	Sure.
Kelly Cervantes:	07:20	There's just so much of what you just said that I want to point out how that first doctor in the emergency department didn't recognize it. And so they brought in someone else and just how important that was because it's still so shocking to me that infantile spasms is considered rare, one in 2000 births, but you think of how many babies are born in a region that a hospital serves and you really do hope that within that emergency department, especially at a pediatric hospital, and CHOP is world-renowned, that they would be able to recognize that. So, there's just so much awareness and education that we have to

do within the medical field, let alone parents being aware of that.

Kelly Cervantes: 08:10 And then you get into the hospital and the relief that you mentioned at having an answer, having known in your gut that something was right and having that validated. I think that there are so many caregivers out there that feel that in the bottoms of their heart, even though it's this devastating, potentially devastating diagnosis, just to have an answer, it can be such a relief. So you get started on ACTH, this crazy, horrific steroid. What did that process look like? How long were you on ACTH and what were the side effects that Madison and your entire family experienced from that?

Lissy Griffin: 08:58 So, CHOP was great about, we actually did an education class, my husband and I, where they taught us exactly how to do the injections, how to make sure we had the correct dosage. So we were actually in CHOP for a week while we waited for the medication to be delivered to our house and continue education there. And then she was on a high dosage. So two injections daily for two weeks, and then a weaning period of two weeks to get her off of it because like any steroid, you don't want to just stop it. You want to slowly wean off of it. Madison herself was kind of like a roid-raging adult male, I would say. She was angry. She went from being a very smiley, happy little baby to a very angry and she looked uncomfortable and unhappy most of the time, which I think was the hardest part. Is you get this diagnosis and you think, well, now we're on the mend. And you kind of come home expecting there to be, get better, get better. And you realize, well, this is a whole different thing.

Lissy Griffin: 10:09 We were lucky that she didn't have spasms after we started ACTH, but it was definitely hungry constantly. I was breastfeeding her and she probably ate every hour to two hours throughout the entire day and night. And just in general, pretty moody. And then she gained about three pounds in the first two weeks. So she went from, she was already kind of a chunky baby, to what they call moon face. And she just was this big round face, chunky arms, which we thought was adorable, but it came with its own side effects of my husband and I. When your child's very irritable, you become a bit more irritable, especially when you might be around other people. "Oh, what's wrong with her?" Things like that, where you can't comfort her the way that you could before. So that was the harder part.

Kelly Cervantes: 11:03 And you don't have this... ACTH is an incredible treatment for IS, but it is not a cure. So you don't have a lot of answers. And you

		said that you have gone through some diagnostic testing and you weren't sure what the cause was. And I think the majority of infantile spasms patients don't find out what the cause is, which is horribly frustrating, because then you're stuck treating the symptoms of the seizures and the hypsarrhythmia.
Brandon:	11:39	Hi, this is Brandon from CURE Epilepsy. In 2013, CURE Epilepsy launched the infantile spasms initiative with $4 million in funding. Research discoveries from this initiative have led to a potential treatment for reducing spasms and decreasing side effects. To learn more about infantile spasms and the ongoing research to find a cure, please visit cureepilepsy.org/infantile-spasms-initiative. Now back to Seizing Life.
Kelly Cervantes:	12:10	Let's see. For new parents who are hearing about infantile spasms for the very first time, or they think that they just saw their baby do something strange or abnormal, they hear startled reflex, what do you recommend that those parents do if they are seeing signs that are concerning?
Lissy Griffin:	12:34	I have had a lot of parents reach out to me over the last few years after I had tried to do some of my own awareness for Madison. And I tell almost every single person to go to a children's hospital emergency department. I always feel like it's better to be told it's nothing, it's startled reflex, it's acid reflux and have that, rather than question yourself or your gut and then wait a little bit longer. Infantile spasms is considered a medical emergency. So you want to get it treated and diagnosed right away for a better outcome in the future. So I always tell people to go right away to an emergency department. At the very least, videotape it. I videotape every single time Madison does something weird, even now. Just to say that I have it in my back pocket to show to somebody if I need to.
Kelly Cervantes:	13:32	Excellent, excellent advice. And where did you find support and information both during your journey and after?
Lissy Griffin:	13:44	Pretty much immediately when we were in the hospital, I looked on Facebook for infantile spasms and found there was a community page, as well as just an informational page. And the infantile spasms community page has, I would say at this point, 500 parents globally, that will post updates on their children. They'll post questions or videos, or really anything from advice on how to continue treatment. And it really was helpful. I immediately posted a picture of her on there and said, "I'm in CHOP right now. My daughter was just diagnosed. Can somebody tell me if their child was developmentally on track,

		had no underlying issues, what their child looks like today?" Because all you're really looking for in those moments is a little bit of hope. Even that's not the track you're on, it just is what I needed to hear and it was so helpful. And since then, over the last three years now, I've continued to kind of support other parents who are going through it and paying it forward to them to be an advocate for them and to kind of point them in the right direction when I can.
Kelly Cervantes:	14:57	What as a community do you think that we can do to better educate parents and caregivers on infantile spasms?
Lissy Griffin:	15:06	I always felt like once I joined the infantile spasms community and realize that nobody's aware of infantile spasms, unless you're dealing with it directly, even our pediatrician said the pediatric office had only seen, I think maybe two cases. So it just makes me feel like education and awareness for pediatricians, for any sort of medical student going into pediatrics, for daycare workers and caregivers of infants. I feel like there was a lot of education concerning new parents and things like SIDS, but there should just be the same amount of education when you're talking one in 2,000 infants. To me that's still a very high number and I still think that there's a lot of children that go undiagnosed and that that number could even be higher. So I would like to see education across the board for anybody that is going to be dealing with infants, just so that there's some sort of early diagnosis and detection.
Kelly Cervantes:	16:10	Why is that early diagnosis and detection so important?
Lissy Griffin:	16:14	From what we understood, if we had not brought Madison in when we did, and we had waited a month or waited six months and kind of let these go on, that what it was doing, especially the hypsarrhythmia aspect was almost causing her to have these blackout moments of this disconnect in her brain waves. And the longer you have that, the more permanent that becomes. And down the road, you're looking at developmental delays, physical, mental for possibly the rest of her life, if it went undiagnosed for too long.
Kelly Cervantes:	16:52	And so now my favorite part is that I get to ask you how Madison is doing today.
Lissy Griffin:	16:59	Madison is the best thing. She's sweet. I always say she's a little bit sassy. She's three and a half years old, and she's smart and fun and kind. People who meet her now would have no idea what she went through as an infant.

Kelly Cervantes:	17:20	That's absolutely amazing to hear. And have you seen any other seizures since she was weaned off the ACTH?
Lissy Griffin:	17:30	Madison had one seizure two weeks into treatment. The day that we were supposed to start weaning, she had a spasm just on her left side. And then I videotaped it as I do with all things and sent it to the epileptologist who we were actually introduced to once we started the treatments. And they to continue weaning, she had to clear EEG since treatment. So they weren't concerned. They said sometimes it's just when you're weaning off of it, your body can have a weird reaction. But since then, that was May 2018, we haven't seen any spasms since.
Kelly Cervantes:	18:07	Now, are you concerned that the epilepsy could return at some point in her future?
Lissy Griffin:	18:16	That's always been a concern of ours. Our epileptologist said there's no way of knowing. They can't say for sure, "You did ACTH. She's graduated. She's done." We did go back every six months for a year and a half. And because she was doing so well, we don't go back regularly now, but they essentially said any sort of head injury could bring about seizures for her. That epilepsy isn't totally off the table, but that so far, this is a good sign for her and for the future.
Kelly Cervantes:	18:47	I understand that Madison has a baby brother now, Liam. Do you have any concerns about Liam developing infantile spasms?
Lissy Griffin:	19:01	I would say Liam has been almost a different mental game to get past. He is just almost to the day, the age that Madison was when she started having spasms. So I oftentimes relate to it almost like PTSD. He has crazy startle reflex, which makes me question everything. But so far he seems to be doing fairly well. We did talk with neurology before we decided to have another trial and just said, "What are the odds?" They said, "We can't tell you that. There's not enough research." It most likely was a genetic mutation with Madison. So most likely, he would be fine, but it's definitely been interesting going through all this again with another and going back to that time with her.
Kelly Cervantes:	19:51	Interesting once you know all the things that can go wrong. It opens up these doors and it can be terrifying.
Lissy Griffin:	20:01	Yeah.

Kelly Cervantes:	20:02	Well, I am just so excited to hear that Madison is doing well. These success stories just speak volumes to how important research is and how important pushing science forward and these treatments are. And also, I think speaks to just the how... I mean, we talk about epilepsy. It should be epilepsies. There's so many different types of epilepsy, but even when you get into infantile spasms and the number of different causes and outcomes, but it just gives me so much hope to hear stories like yours and Madison's that science was able to make a difference in the outcome of her life and her future. So I'm just so grateful for you to share your family's story and to bring hope that is so desperately needed to so many other families. Thank you. Thank you. Thank you. I hope to see you in person at some point.
Lissy Griffin:	21:06	That would be wonderful.
Kelly Cervantes:	21:10	Thank you Lissy for sharing your story with us and for your efforts to raise awareness and encourage better education about infantile spasms for parents, childcare providers, teachers, and pediatricians. Infantile spasms are considered a medical emergency and can deeply impact a child's physical and mental development. As Lissy's story highlights, early intervention can be a key to better outcomes. If you suspect an infant is experiencing IS, please consult a physician immediately. And if you feel the need for a second opinion, don't hesitate to get one. Well, there is still much to be learned about IS. Progress has been made and research continues. CURE Epilepsy has been at the forefront of research into infantile spasms. Please help us continue to push IS research forward by visiting cureepilepsy.org/donate. Your support and generosity are greatly appreciated. Thank you.
Legal Disclaimer:	22:14	The opinions expressed in this podcast do not necessarily reflect the views of CURE Epilepsy. The information contained herein is provided for general information only and does not offer medical advice or recommendations. Individuals should not rely on this information as a substitute for consultations with qualified healthcare professionals who are familiar with individual medical conditions and needs. CURE Epilepsy strongly recommends that care and treatment decisions related to epilepsy and any other medical conditions be made in consultation with the patient's physician or other qualified healthcare professionals who are familiar with the individual specific health situation.