

Seizing Life, episode 98
Medical Cannabis: A Life Changing Journey for Mother and Son
Guest: Sarah O'Hanlon
(Transcript)

- Kelly Cervantes: 00:00 Hi, I'm Kelly Cervantes and this is Seizing Life, a biweekly podcast produced by CURE Epilepsy.
- Kelly Cervantes: 00:17 Today. I'm happy to welcome Sarah O'Hanlon to the podcast. Sarah's son, Owen, was diagnosed with infantile spasms at five months old and has experienced seizures all his life. When they ran out of treatment options in their home state of Virginia, Sarah took the bold step of moving to Colorado where medical cannabis was legal in hopes that it might bring some seizure relief for her son. Sarah is here today to share their story and tell us how that journey to Colorado ultimately set her on a new career path. Sarah, thank you so much for joining us today. I think our conversation is going to pique a lot of people's interests, but before we get there, can you tell us how epilepsy first entered your life?
- Sarah O'Hanlon: 01:03 Of course. My son Owen was born in 2005 and had no complications, had a normal pregnancy and delivery. I have two older children as well, so there were no surprises. And as we were going along and he was a couple months old, I noticed that he was having a lot of startles and he was doing it in a very repetitive pattern fashion. So I brought it up to his pediatrician and they basically said it's normal neurological development, they will grow out of it. And it persisted and he just continued to have these very rhythmic startle episodes.
- Sarah O'Hanlon: 01:54 Just before he was five months old, I really just couldn't listen anymore to it being normal neurological development. It just didn't seem right. So I took a video of it and brought it to his pediatrician and said, "I've done a little research on this and I'm concerned that he has infantile spasms." He saw the video and agreed that I should have him tested with an EEG. And so he, at that time, wrote an order for an immediate EEG, sent us to another hospital that has an epilepsy unit. When we got there to the hospital, he was set up with an EEG and the doctor came in after a short time and he said, "You're right." And so that was the first day that we realized that in fact our concerns were warranted.
- Kelly Cervantes: 02:54 It's so devastating because you do your Google dumpster dives on the internet to look at infantile spasms and it's terrifying.
- Sarah O'Hanlon: 03:03 It is terrifying and it's also hard not knowing because you have so many questions and so few answers when there's things that just aren't very common and there aren't other parents to talk

to about it. So it really felt very isolating, especially after the diagnosis.

- Kelly Cervantes: 03:22 What did Owen's treatment journey look like from that point?
- Sarah O'Hanlon: 03:27 Well, he was admitted to the hospital pretty much right away, and he was there for a week. He went through lots of different tests. They did everything from genetic testing, blood testing, EEGs, MRI, spinal tap, everything. I mean, it was exhausting for all of us. And so at that time, when he was discharged, they didn't really find anything. The MRI didn't show anything that was abnormal. The EEG showed very mild hypsarrhythmia, but he, at that time, and we were very fortunate that he did not show any signs of clinical regression of his development. He just was doing okay. He was sitting up and he didn't lose any of those skills, which is one of the hallmarks of a catastrophic epilepsy type like infantile spasms. So we were very hopeful that this could be resolved quickly using ACTH, which he was on then a regimen of that and I had to give him injections in his thighs every day for a number of weeks. That did make the hypsarrhythmia pattern on his EEG dissipate over time and then it disappeared.
- Kelly Cervantes: 04:46 And then along with the ACTH eliminating the hypsarrhythmia, which is a brainwave pattern that shows up in the EEG, did it also eliminate his seizures because the two are different?
- Sarah O'Hanlon: 05:03 It did not. He still continued to have what was considered to be mild spasms, and it was especially during times of sleepiness, when he was nursing, and when he was just waking up, and sometimes when he was just tired right before he would go to sleep. So for a little baby, as you can imagine, that's pretty much all the time. He was either doing one or the other at that young age. So he was having thousands a day of these epileptic spasms or infantile spasms as they're called and they didn't go away and they still persist. He still has them upon waking.
- Kelly Cervantes: 05:44 And how old is he now?
- Sarah O'Hanlon: 05:46 He's 17.
- Kelly Cervantes: 05:48 So 17 years of managing seizures. What did the doctors tell you in terms of treatment? What did they tell you in terms of prognosis?
- Sarah O'Hanlon: 05:58 As you might imagine, prognosis for any catastrophic epilepsy is very guarded. There really isn't a clean manual saying, "This is

how it's going to go, and this is what you're going to take, and this is going to work, and we're going to go from here to there.” It's really an individual thing and it's a trial and error. We really didn't know what his outcome, his prognosis would be. It was very scary. What we were very grateful for, and in his case, we were very fortunate, that he was developing, yes, slower than his peers, but he was still moving forward. A lot of children with this diagnosis don't do that or they regress significantly, and things are not nearly as hopeful in that way as far as they're gaining skills as they get older. He was put on a number of different medications. We went through about nine medications that were unsuccessful.

Kelly Cervantes: 07:00

So you go through this exhaustive list of potential treatments and medications and your son is still having seizures. What led you to cannabis?

Sarah O'Hanlon: 07:16

I really had no experience and I didn't have any ideas about alternative treatments. We were on the ketogenic diet for seven months, which was very difficult, but it never changed his seizures at all. So when he was 10 years old, he began having complex partials and they just interrupted every normal aspect of his life. It didn't take long after those complex partial seizures started that we started to see them generalize into secondary generalized seizures. It was then that we realized that we were scared to death and did not know what to do and we had no answers on where to go. You do anything and try anything as long as you consider it to be safe.

Sarah O'Hanlon: 08:09

And so there was a lot of, “Okay, it's a plant, it should be safe, but it's not legal.” And the reasons behind that. It was all very confusing. And it is to parents still today, of course, and I understand that for sure. So after lots of conversations and very heartfelt emotional moments with his seizures, we had heard about other parents that were traveling to Colorado to seek medical cannabis, where it is legal and they have access to it. So by the end of August, I was on my way to Colorado with my son and we got an apartment there in Monument, which is just north of Colorado Springs.

Brandon: 09:03

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: 09:28 Here you are splitting up your family. Your sons, and your older children, and your husband are staying in Virginia. You are moving to Colorado with your son to try and find answers. I'm not sure that people realize the lengths that some families have to go to, to find those medical treatments that are accessible, but not just that are accessible, where there are doctors who can guide them and help them with dosing and with measuring outcomes.

Sarah O'Hanlon: 10:08 Yeah, it was very scary. We didn't really know what to expect. As I said, I really had no experience. So it was almost that you know there's lots of questions, but you really, at the time, didn't even know which questions to ask. But luckily, I am a big time researcher. I did a lot of looking into things and I looked up medical doctors that also were cannabis advocates and experts in that area. And we were lucky enough to be connected with a doctor in Colorado Springs that was very helpful in guiding us.

Kelly Cervantes: 10:46 And what did you try first?

Sarah O'Hanlon: 10:48 Well, we first tried CBD, and we actually did try that before we left. It was a product that was purchased online. At the time, I really had no experience as to what to look for. And that, looking back, is very scary to me because at the time it was, as it is still in many states, very wild, wild west. There's just so many products out there and they don't have any obligations to make claims. There's nothing that is enforcing them to actually have in the bottle what they claim that is in the bottle. So there's definitely a lot of variability and even testing can sometimes be inaccurate even if the testing has been conducted. So at the time, it didn't really do much for him at all.

Kelly Cervantes: 11:37 I also imagine that you were dosing that on your own or based on an online forum versus working with a medical professional. I know that when we did it, that's when we first tried CBD, I was doing it based off of a Facebook group, what they suggested that we do, which is crazy to think about.

Sarah O'Hanlon: 12:02 It is. We are all in this new territory that we're learning so much so fast. Things are changing all the time and better understandings of different compounds within the plant and how they work synergistically. At the time, even in 2015, which isn't all that long ago, there was really not a lot of information out there. And so those few people that were considered experts in that field were really a gift, as well as the families that supported us along the way. I mean, that to me was one incredible aspect of our journey out there was how well we

were received by people we've never met before. It was incredible.

- Kelly Cervantes: 12:47 So you had tried CBD by purchasing it online when you were in Virginia and then you moved to Colorado and you are now working with a doctor and you tried CBD again. Does it work at this point?
- Sarah O'Hanlon: 13:03 We initially tried CBD because we wanted to work with her guidance, which was definitely much needed. And we didn't see a lot of results. We did see a little bit of a reduction in his seizures, but they weren't going away in his waking myoclonic clusters, which I explained before. They were persistent. So we decided that we would introduce a low dose of THC within that CBD oil mixture or formulation. And we definitely saw a reduction and he actually was sleeping better too, which was really nice because it was very hard for him to have a good night's sleep, as you imagine.
- Sarah O'Hanlon: 13:50 That started to improve his days. So he actually became a lot happier. He became more conversational. He was more active and he felt a lot more confident too, which was really fun to watch and watch that evolve. The THC definitely helped and improved his overall health I feel, and it wasn't impairing in any way. It was a low dose. So he wasn't experiencing any sort of impairment from it whatsoever. And of course back then, I wasn't really as aware, but now of course, the CBD can also mitigate some of those psychoactive effects of THC if given in the right ratio.
- Kelly Cervantes: 14:32 I can only imagine how special that time must have been to have with just you and your son. However, the rest of your family is in Virginia, on the other side of the country. That must have been so challenging and so difficult to be separated from them like that. You couldn't stay in Colorado forever. At some point, you had to go back to Virginia. What happened when you went home?
- Sarah O'Hanlon: 14:59 Yeah, that was incredibly hard. It was hard talking to my kids on the phone. I missed them so much, and it was just a difficult time for all of us because nobody knew what to expect. We didn't have any sort of promise that things would actually be worth all of the stress and upending of our lives. So when it came to the point where it was just not financially feasible for us to maintain two households, we returned to Virginia. And I had some oil that I had from his supply that quickly ran out and there we were again without any access. And it was very scary because we didn't quite know what to do and how we would

gain access because in Virginia, at the time, there wasn't any state regulated formal medical cannabis program.

- Sarah O'Hanlon: 16:01 So it was very scary and we basically had no access to the cannabis that was helping him and making him better. He never achieved pure seizure freedom. I do want to emphasize that, but I also want to emphasize that it made his life better and it did reduce his seizures. It increased his recovery. He bounced back much faster and he was able to sleep better, which made his days better. I think that all of that working together was really just a true gift to him and to us. Actually, seeing more than just glimpses of him being a typical kid. So it was very hard when that all left.
- Kelly Cervantes: 16:45 Which makes sense as to why you started lobbying as hard as you did to try and get something passed in Virginia. What was that process like?
- Sarah O'Hanlon: 16:55 Well, I connected with some wonderful people on Facebook, of course, and they were parents like me who had children with catastrophic forms of epilepsy. They were really just the most incredible parents. They were actually doing all this work long before I came into the scene. I was just so grateful that they were welcoming to Owen and I, and our interest in helping them in this amazingly difficult task of getting Virginia to pass a law for CBD for pediatric epilepsy.
- Sarah O'Hanlon: 17:38 It wasn't that we were only fighting for our own kids. Of course, we were fighting for all people who want to have this access and need it desperately as at least an option or a tool in their toolbox. But at that time, as many people know, in the legislative process, you have to go in baby steps. And that was the first step, which was for pediatric epilepsy and that passed. So we were able to have access to CBD and THCA in small potency doses. Of course, with that, it was only affirmative defense. So we didn't have access to it. There weren't medical cannabis dispensaries in which to access, tested, regulated, safe medicine within our state.
- Sarah O'Hanlon: 18:27 So there was a lot of issues with that because we had this bill, but we still couldn't access it. You can't get THCA online because it's considered a THC. So it's not legal to purchase online. So we continued the struggle. That was just the beginning. And things evolved over time. And as you well know that Virginia has now developed a medical cannabis program and it is much better than it was. I mean, we still have ways to go, but the access is gaining as we move along.

Kelly Cervantes: 19:09 But it's taken a fight and it has taken significant effort. And on your part, some additional education. Talk to us about the master's program that you enrolled in and have since graduated from.

Sarah O'Hanlon: 19:23 Yeah. As I said before, I love to research. I'm constantly trying to get better understanding of this dynamic plant and what it does for not only people with epilepsy, but with other conditions as well. I saw an ad and couldn't believe what I was seeing, that there was actually a master's program, Master's of Science in Medical Cannabis Science and Therapeutics. It is at University of Maryland School of Pharmacy. Dr. Leah Sera is the program director and it is a dynamic group of professors from the pharmacy school. All incredibly well-educated and super excited and motivated for this program to inspire and educate people like myself, who are interested in advocating for this amazing plant and helping people to get better educated and learn the ins and outs of how to navigate this complex medical intervention.

Sarah O'Hanlon: 20:30 That's how it all started, is that I saw this advertisement and I applied to the program. I wasn't sure I'd get in because it was with the school of pharmacy. I hadn't had any science background in my life, but of course, I got in and I did very well, and it was an incredible gift to me and I credit my children for inspiring me. All of them. They were very supportive.

Kelly Cervantes: 20:57 You are a supermom of the first order going above and beyond for Owen and for the community and educating all of us. I guess, what are some of the issues that still exist today around medical cannabis, both access and research?

Sarah O'Hanlon: 21:20 Well, of course, federal prohibition makes it very challenging for prospective researchers to gain access not only to the medicine that they need in order to use it for these clinical trials, but also the affordability. It's very, very expensive. It's just incredibly challenging to get an FDA approval for conducting these studies. But as far as for going forward from a patient standpoint, really it's still access. Even when there are medical cannabis programs, a lot of them are really geared toward recreational users. And even when there isn't necessarily strong emphasis on or legal recreation in that state, it's sometimes difficult. Because, as an example, Owen has responded very well to an intranasal delivery mechanism for cannabis medicine. And it really does help him with his seizure clusters. It will reduce them or eliminate them completely. And so there are not many medical cannabis dispensaries that actually have and carry that

intranasal device with it formulated specifically for intranasal delivery.

- Sarah O'Hanlon: 22:42 So access to this right routes of administration for patients. All patients is incredibly challenging. And as recreational programs continue to evolve and grow, I do worry that the medical cannabis patient focus might diminish. That is a big fear of mine and many of us in this situation.
- Kelly Cervantes: 23:07 That's fascinating to think about how the two recreational and medical, I think so often we just sort of piece them together in our minds, but that one can very much harm the direction of the other. Bearing all of this in mind, what is it that you hope to be able to do with your degree and with your advocacy from this point forward?
- Sarah O'Hanlon: 23:34 Well, my goal has been from the beginning is helping other families like mine and to help support them and educate them. I am not a clinician, I am not a doctor, so I can't offer clinical advice, but I can certainly with the degree in my background and as a parent of a child who's been through much of the trials and all the turmoil in the process of finding the right medicine for them, whether it's cannabis or otherwise, I would like to be able to offer that education to those families who would like to consider cannabis as an option for them.
- Sarah O'Hanlon: 24:15 There's a lot of things to consider. It's a very dynamic and complex plant with lots of things to consider before embarking on cannabis as medicine. Contraindications to other medications, especially anti-epileptic medications. For me, I want to be very transparent with clients that have questions and encourage them to have an open conversation with their doctor. Because sometimes people embark on this and they don't discuss it with their doctor for the clear reason that it's still taboo and there's a lot of stigma. But in some cases, and in many cases in fact with epilepsy, it can be counterproductive because they can run into contraindications with their medications that they're taking, or they want to take away all those medications abruptly, which is very dangerous and definitely not advisable at all.
- Kelly Cervantes: 25:15 You talk about the cannabis plant being as complex as it is. You talk about THCA or the formulas essentially of the different oils or the nasal sprays or whatever. What is it that makes each of those different or could make one effective for somebody and a different one effective for somebody else?

- Sarah O'Hanlon: 25:44 Well, the cannabis plant is an incredibly dynamic plant in that there are many different types. They are often referred to as strains, but the formal and correct term is chemovars, and each of these types of plants have a different cannabinoid profile. There's type one, two and three. Type one is high in THC, and that's the one that has gained obviously the most notoriety in the past 100 years. Type two is a combination of CBD and THC, and type three is CBD dominant, which is what you often see with regard to in the treatment of epilepsy. In addition to those three different types is varying levels of concentration of those cannabinoids. In addition to that is the varying levels of concentration of terpenes. Terpenes are an incredibly important part of the synergistic effects that cannabis has when it is used as a medicine. So there are different types of terpenes, which can be considered more desirable for various ailments.
- Sarah O'Hanlon: 26:56 So not only are you working toward finding that correct chemovar that fits your type. It's individual, it's very individual. Dosing can be individualized. It's different for each person. One can have therapeutic benefit from a very low doses and others might need a moderate or even higher doses. The importance is to always start very low and under your doctor or practitioner's guidance. So just between the cannabinoid profile and the terpene profile, those are two very huge components that make it very dynamic and complicated.
- Sarah O'Hanlon: 27:39 In addition to that, as you explained, as you said, was the routes of administration. There's so many different routes of administration for cannabis. You can take it orally, sublingually, intranasally, within a suppository, transdermal. You can have a patch on your arm and edible of course, in different foods. Though I'm very cautious to recommend edibles for all the reasons that they can be very highly variable and the bioavailability is not consistent.
- Kelly Cervantes: 28:09 It's so fascinating if someone is like, "Well, have you tried CBD? Have you tried THC?" And they don't realize that there are all of these variables that just because you've tried one specific formula or one specific way to administer, it does not mean that the entire class of drug does not work for you or for your child. I think that that information is so incredibly valuable that maybe there are more options out there that we're just not aware of because they're not accessible or they're not being talked to us. I wonder, what do you see on the horizon or in general for the future of cannabis in treating epilepsy?
- Sarah O'Hanlon: 28:59 Well, to me, the bottom line is education and advocacy, and I'm hoping more and more people can get out there that are like

myself who can provide support. And I think that that's growing. That educational gap is to me the single biggest factor in progressing in our understanding of medical cannabis with the treatment of epilepsy and other conditions as well, of course.

Sarah O'Hanlon: 29:27 Research is also extremely important and it's what we were taught in school to try to emphasize the evidence behind it. The research is what's so important. And I think that with all of their new research coming out, I think things are going to explode in the way of our understanding and our grasp of how it works. Not only how it works, but for whom it can benefit. And hopefully, that will help people to feel a little less fearful like we did when we really didn't have any of that information. This kind of thing is actually being incorporated into medical schools and clinical educational programs now more than it was because they're realizing that it's important, not only for their understanding of the plant, but their understanding of how that plant can interact with medicines that they might prescribe.

Kelly Cervantes: 30:21 I could not agree with you more on the importance of research in this field and in general. What advice do you have for parents, caregivers, patients who are interested in learning more about CBD and THC for the treatment of epilepsy?

Sarah O'Hanlon: 30:43 Well, I think that one of the great websites that I would recommend is Americans for Safe Access. It is an excellent resource for patients and practitioners. It's got a section for patients specifically. It even has information on medical cannabis as it applies to them, or for them to learn for themselves and information for them to share with their practitioners. It's a really great resource. It's a wonderful group of people who are advocating for, just as it says, safe access for patients like my son and education for their loved ones, their caregivers, and for the patients themselves. In addition to that, there are some wonderfully talented and very, very evidence-based medical cannabis practitioners that can offer televisits. I know Dr. Sulak is in Maine and Dr. Bonni Goldstein, she's in California. These are wonderful people who are very committed to the research behind medical cannabis, its benefits, and explaining and outlining its potential risks. So I think that there is a lot out there to be had in the way of resources. It's a matter of knowing where to go.

Kelly Cervantes: 32:01 Sarah, this has been so incredibly informative. I personally have learned so much and I am so grateful to you for sharing your time with us, for sharing your education, and your experience. And I know that we all wish you and Owen a healthy and

hopefully, a seizure-reduced future as you continue your journey.

- Sarah O'Hanlon: 32:28 It was my pleasure to be here. Thank you.
- Kelly Cervantes: 32:34 Thank you, Sarah, for sharing your journey with us. We wish you the best of luck in your new role as a medical cannabis educator for patients and doctors. As Sarah made clear, using medical cannabis for epilepsy has resulted in some intriguing anecdotal evidence, but much more research needs to be done to increase our knowledge and gather data around its efficacy.
- Kelly Cervantes: 32:57 CURE Epilepsy has understood the necessity and value of scientific research since it's founding more than 20 years ago. In that time, we have raised more than \$85 million in pursuit of a cure. We hope you will help us in our mission to end epilepsy by visiting CUREepilepsy.org/donate. Through research, there is hope. Thank you.
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