Seizing Life, episode 89
A Remarkable Journey to Seizure Freedom Through the Ketogenic Diet
Guest: Jim Abrahams

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 excited to welcome Jim Abrahams to the podcast. If that name sounds familiar, it's because Jim is one of the creators of some of the biggest comedy films of all time; including Airplane, Top Secret, and The Naked Gun.

Kelly Cervantes: 00:32 In 1993, in the midst of writing, producing, and directing successful films and television shows, Jim's infant son, Charlie, was diagnosed with epilepsy. Jim is here today to tell the story of Charlie's treatment journey from medication, to surgery, to the ketogenic diet. It's a story that is both frustrating and remarkable, and which highlights the importance of education and patient advocacy in the epilepsy community. And, the potential of the ketogenic diet as a treatment for epilepsy.

Kelly Cervantes: 01:01 Jim, thank you so much for joining us today. I'm so excited for our conversation. To start things off, can you tell us about how Charlie's epilepsy first appeared and was diagnosed?

Jim Abrahams: 01:18 All right, well, Charlie was just about one year old. After having a pretty normal first year and, right around his first birthday, I was pushing him on the swing in the front yard. And I noticed he just kind of flipped his hand in the air. And I didn't think much of it, but I asked Nancy whether she'd seen anything like that. And she said, "yeah", she'd seen a bunch of things.

Jim Abrahams: 01:46 And so, we made an appointment with a neurologist. Actually just with his pediatrician. And then, the pediatrician said, "You should be seeing a neurologist." And by the time we, made an appointment with a neurologist, Charlie had his first tonic-clonic seizure. And, you know, that's not very difficult to diagnose. It went on for about 20 minutes, and we called the rescue squad, and all that kind of stuff. And, that was the beginning. And the seizures rapidly escalated in duration, frequency and severity. I would say within a week, or two of that first kind of subtle thing.

Kelly Cervantes: 02:40 And, what did the neurologist tell you when you finally got to meet with them? Did they give you a specific diagnosis?

Jim Abrahams: 02:52 Eventually, Charlie was diagnosed with what they thought was Lennon-Gastaut syndrome. And they told us that they would try a drug, phenobarbital, because it'd been around a long time, and we were sent on our way.

Kelly Cervantes:	03:12	Yeah. Hand you the pills, and see if they work. Pat and a handshake. And what did his treatment journey look like from there? I know that the phenobarbital didn't work.
Jim Abrahams:	03:23	Correct. And so then, there was a rapidly escalating bunch of drugs. I think this is 1993. So, at the time, there were about eight or nine anti-epileptic drugs available. So, we rapidly went through all the drugs. And, at the same time, none of them worked. They all had adverse effects and, at the same time, I was sort of at a peak in my career in the movie business. And so I didn't know it, but I was inadvertently connected with lots of people who had connections at a lot of hospitals around the United States.
Jim Abrahams:	04:07	So, we wound up taking Charlie to the heads of pediatric neurology at Boston Children's Hospitals, Seattle Children's, UCLA, LA Children's. And he had seizures in all their arms. And they were all in agreement in treatment options. They said there are drugs, and there's surgery, and you're out of lock.
Jim Abrahams:	04:36	So, we tried virtually all the drugs of the day Dilantin, [inaudible 00:04:43], Tegretol, Benzodiazepines, whatever was around. And sometimes there'd be like this brief, what they call, 'honeymoon period' when the drug seemed to be working. But those honeymoon periods were always brief. And the seizures always returned. And, at the same time, Charlie was losing developmental milestones. He was just over one year old. He stopped being able to block, stuff like that.
Kelly Cervantes:	05:16	Yeah. Which just feels so helpless as a parent being told that, just throw a dart at a medicine board, and see which one hits and meanwhile, nothing's working and you're watching your child suffer because of it.
Kelly Cervantes:	05:36	You eventually found the ketogenic diet. But it wasn't easy. How did you come across the keto diet? And what was the response when you presented it to the doctors?
Jim Abrahams:	05:50	Well, after all the drugs failed, and a brain surgery failed, we were pretty much told that we were out of luck. And that Charlie's prognosis was continued seizures and, what they call, progressive retardation. And, Charlie's main doctor was at UCLA. And one day when we were at UCLA after seeing his doctor, I stopped at the medical library at UCLA, not really looking for a cure, or a therapy I mean, Charlie had had seizures in the arms and hands of many of the premiere pediatric neurologists in the United States. They were in agreement. So, I think what I was trying to figure out is how we were going to get

through life with Charlie's devastating prognosis. I mean, what do families do? Is he going to be able to live at home? Is he going to be able to survive? What do you do? And so I went to the library and I think I mentioned earlier that, Charlie's diagnosis is Lennon-Gastaut syndrome.

Jim Abrahams: 07:03 So, I started looking in the back of these medical texts for... I looked up Lennon-Gastaut and right above alphabetically, right above Lennon-Gastaut in the index, in the textbooks, it would say ketogenic diet. So, eventually I turned to that page and what I found was sort of mind blowing. Now, mind you, this was the early nineties. So all the text predating the early nineties talk about the ketogenic diet. Which was developed in the 1921 at the Mayo clinic.

Jim Abrahams: 07:44 And, for decades was a leading and very successful therapy for kids with difficulty control seizures and different doctors, from different hospitals, in different decades, use the same diet on essentially the same patient population and their outcomes were outstandingly similar. Roughly a third. And this is in every decade along the way. You can find these publications. Roughly a third of the kids who went on the ketogenic diet, had their seizures go away. Another third were significantly improved, you know, fewer drugs, fewer seizures, and for about a third didn't work. So, you can imagine at that stage of the game to come across statistics like that was kind of mind blowing.

Kelly Cervantes: 08:46 I mean, those are far better statistics than for most pharmaceutical drugs that you've come across for sure.

Jim Abrahams: 08:52 Correct.

Kelly Cervantes: 08:53 So I love, I feel like going to the medical library is sort of the early nineties version of what I refer to as a Google dumpster dive, which is sort of what my parental generation has done to try and find this information on our kids. Like hoping that there's something else out there. So you find this information, you find this research, you present it to Charlie's doctors and what do they tell you?

Jim Abrahams: 09:16 Well, it's kind of interesting at the, at the same time we, I came across the information about the ketogenic diet in the library, a friend of ours told us about a herbalist who worked out of a strip mall in Houston, Texas, and evidently at herbs that were good for kids with epilepsy. And so we went to Charlie's doctor at UCLA and said, "look, we came across two alternative things here. There's this diet and there's this herbalist who works out of his strip mall in Houston, Texas. And we want to try

		something new. What do you think we should try?" And he said, "flip a coin. I don't think either will work". So, for, actually the last time we took his advice, we flipped a coin. It came up herbalist in Houston, Texas. So we piled Charlie on an airplane and we went to see this guy, nice guy who gave us some herbs in strip mall in Houston and came back and the seizures never went away.
Jim Abrahams:	10:31	So finally, the doctor who wrote the most recent paper out the ketogenic diet, name was John Freeman. And he worked at John's Hopkins hospital in Baltimore. And he had published a paper in 92, just a year before Charlie got sick. So it was kind of hot off the presses and it was published in Epilepsia, the premier epilepsy medical journal. And, in his paper, he chronicled 58 consecutive kids with seizures, as bad as Charlie's and taking as many drugs as Charlie and 29% of them became seizure free on the diet. Another three 30% were significantly improved. So I called Dr. Freeman and I asked him what he thought. And he said, "send Charlie's medical records". We did.
Jim Abrahams:	11:28	And he said, "yeah, I think we should try the diet". So, Nancy and Charlie and I flew to Baltimore and Dr. Freeman, and this is Kelly, a dietician he's been working with since the 1940s on the ketogenic diet, kind of oversaw administering the diet for Charlie. And at the time, Charlie was on four anti epileptic drugs and averaging about a dozen seizures a day. And within two days his seizures disappeared. And, it was kind of miraculous. And at first we went through that same honeymoon period. Is this really working? But, the seizures stayed gone. And within a month, Dr. Freeman had wean Charlie off all four of his anti epileptic medicines. So it was just the diet controlling his seizures.
Brandon:	12:33	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:	12:57	I'm just sort of curious, how did Charlie's doctors at UCLA respond to this?
Jim Abrahams:	13:05	After, I don't know, maybe six, eight months, we took Charlie to see his doctor and he didn't, he didn't say much. I can tell you that now in the intervening years, he has retired and UCLA has opened a ketogenic diet program in their pediatric epilepsy unit that's doing beautifully and they have two full-time dieticians.

So, they have started to use it in their epilepsy program. But, it's kind of interesting I've really never known how he felt.

Kelly Cervantes: 13:44 Now, we tried the diet for my daughter. Unfortunately, she was part of the third that it didn't work for. However, you know, we had the help of dieticians sending us recipes. We had the benefit of keto being far more mainstream. There were ketogenic formulas that we could purchase. You know, we had significantly more resources, more technology to help us. Because it is, it's a difficult diet to maintain all of the measuring and the preparing and, you know. I wonder what that was like for you? Sort of being on the forefront of this diet and not having the resources that parents today. I mean, this was only 30 years ago. It's not like... It really wasn't that long ago, but in terms of technology and medical innovation, it's, it was, it was a while ago. What was that like for your family?

Jim Abrahams: 14:44 It was, it was nuts. You know, there, there wasn't even food labeling back then. So, you never knew if a processed food had sugar added, you know, there's no, no way of telling. And Nancy used to spend hours in health food stores, looking for stuff with no sugar that had some taste to it. Mrs. Kelly, the dietician from Baltimore would fax us meal plans for Charlie to eat. Charlie didn't like the diet. He was really difficult to feed.

Jim Abrahams: 15:23 And as you know, when you have a kid on that diet, they have to eat every bite of every meal and nothing more and nothing thing last for years. So it certainly was difficult. But, you know, everything is compared to what? And when the results were so outstanding, I remember us thinking, well, this is a walk on the beach compared to, you know, holding this kid a dozen times a day and dragging him off to the hospital when the seizures went on too long and watching him drift away from our family because of, you know, drug effects and seizure effects. So, compared to that, the diet, although difficult, was a walk on the beach. But you're right. Back in the early nineties, I think Charlie was one of maybe eight or 10 kids in the world who was on a ketogenic diet.

Kelly Cervantes: 16:26 That just blows my mind to think about. Because I mean, thank goodness, I suppose, that we've come so far. And, now it is, you know, if your child is seen at a major epilepsy center, the ketogenic diet is typically discussed at some point, if those first initial drugs are failed, you know, but for Charlie to has been one of eight or 10 are on this diet. I mean, it's just, it's wild. So I'm encouraged that we've made progress in this, in this area. And I think a lot of that is due to the Charlie foundation, which I really want to talk about. But first, I want to know how long was Charlie on the diet?

Jim Abrahams: 17:09 Well, our experience was kind of unique. Normally kids who do as well in the diet as Charlie after a year and a half or two, can be weaned off and go on with life. But our experience was after the first two years of being seizure and drug free on the diet, when we tried to wean Charlie off, the seizure came back. And, so we put him back on the diet for another couple years and then tried to wean him again and again, the seizures came back. So we put them back. And it's kind of interesting to note that each time we put him back on the diet, the seizures disappeared instantly. So there's a real cause and effect. And then after the third time we put him on the diet, he was on for about a year. And when we weaned him, the seizures never came back.

Kelly Cervantes: 18:06 Ever?

Jim Abrahams: 18:07 Ever. So he was six then. And he just turned 30 and he's never had another seizure, never taken another anti epileptic drug, never eaten a ketogenic diet meal. Trust me. In all those in all those years.

Kelly Cervantes: 18:27 That's incredible. Now, how is Charlie doing today? Have you seen any long lasting effects from the seizures or from the various treatments?

Jim Abrahams: 18:39 Well, he does have some autism. First couple of years of brain development and the most important, and certainly he was sick at least for the second year of his brain developing. Nobody can tell us whether he would've had that autism if we had started the ketogenic diet in an appropriate amount of time. But he's very happy. He has a certificate in early childhood education. He's worked at a preschool. That's affiliated with the salvation army for the last eight years. Working with little kids and he loves his job and he's been playing piano beautifully for 20 years. And he's been boxing since he was, I don't know, 10, 12 years old. So, and he's, you know, when he was really sick and we would go to a new doctor, Nancy's first question to the doctor was never, "can you stop these seizures?" Or "can you get rid of some of these drugs?" Her first question was always, "can he be happy?" And, Charlie is a happy guy.

Kelly Cervantes: 20:03 What else does a parent want at the end of the day, right? You know, how did all of, you know, this experience affect your opinion of medical approaches to epilepsy and, or the healthcare system in general?

Jim Abrahams:	20:21	I'd say that this kind of fickle and nobody really irons it. That there are forces at work in our healthcare system. There really have nothing to do with good health. And the more, the sooner we go through that learning curve and figure out that drug companies make billions, medical device companies make billions, food processing industry makes billions, diet therapy make zero. And it's very kind of work intensive and that, and doesn't generate revenue. And even so, insurance companies are not big fans of reimbursing dieticians. Where Elizabeth Thiele, who runs pediatric neurology at Mass General, talks about how, if she wants to prescribe ACTH hormone therapy for a kid with infantile spasms, which costs about $250 or $300,000 and lasts for three weeks or something. She can get that reimbursed with a stroke of pen. But if she wants to get a dietician reimbursed for working with a few kids, it's a big struggle with the insurance companies. And, so that's the opposition.
Jim Abrahams:	22:04	And the sooner we get our minds around that the sooner, I think that the learning curve we go through is that we are largely in charge of our own medical destinies and the medical destinies of our children. And at first that's kind of daunting. A little bit scary. But once you adopt that theory, and I know this is a cliche word, but it's kind of empowering.
Kelly Cervantes:	22:32	The best piece of advice I got when my daughter was first diagnosed was from a friend's mother who had a rare disease herself. And she told me to have the fight. And I'll never forget that, you know, to have the fight for my daughter to have the fight with the doctors, to, you know, to have the fight. To not just blindly trust. You're 100% spot on. We have to empower ourselves to find those answers. So, to that extent, you have created the Charlie foundation. I mean, years ago now, to help do just that. To make patients aware, to empower patients with information, to make sure that the epilepsy patient population is not just aware of the ketogenic diet, but also that, ideally that practitioners are out there actually prescribing it. So what, what did you find in organizing and working through the Charlie foundation? What were the hurdles to get from where we were in 1992 to where we are today?
Jim Abrahams:	23:46	What has stuck in my CRA the most from Charlie's experience is that nobody told us. Nobody let us know. We didn't have the information. So from the get go, the Charlie foundation's mission has been to get objective information to people about diet therapy, so that they can make informed decisions in conjunction with their healthcare worker. That's always been our, you know, laser vision goal. And I mean, I think at the heart

of the problem is that, physicians are not taught diet therapy. It's just, even though it's been around forever. And even now, though, there is a century of documentation of its efficacy. And even though now in the last 20 years or so, there's been an explosion of science regarding diet therapy, metabolic therapy. There's physicians who don't really know about it.

Jim Abrahams: 25:04 So I think that is at the heart of the problem. And that includes even dieticians during regular dietician school are not taught ketogenic diet. So the dieticians who are proficient in administering the diet have to have special training. One of the things we do at the Charlie foundation is we have a list of independent dieticians that we have vetted, who are experts in administering the ketogenic diet. And you can find it on our website. And they work independently, if that's of interest.

Kelly Cervantes: 25:46 That's amazing. Thank you. So what would you tell a family, parents who their child has just been newly diagnosed? What would you want them to know about the epilepsy journey, but also about the ketogenic diet on its own?

Jim Abrahams: 26:05 Yeah, that's kind what we do. We get contacted by people who are new to epilepsy, as opposed to, you know, 28 years ago when we started the Charlie foundation. And I was just this lone dad standing on a soapbox, yelling and screaming. Today there's, there are lots of physicians and scientists or advocates of the diet. So there are published consensus guidelines, which we can send to people written by many of the world's premier epileptologist and dieticians that talk about administering the diet. And the key quote to me in those in the guidelines is the diet should be strongly considered after the failure of two antiepileptic medicines. And that's considered that's true for adults too. But that is, that's what the medical professionals say today. We talk to parents all the time, as I mentioned in the one piece of advice that I've given more than anything over all these years and particular to moms is, "trust your instincts".

Kelly Cervantes: 27:33 Yeah, absolutely. Jim, thank you so, so much for chatting with us today. Thank you for all the work that you have done on behalf of certainly my family and so many other families who are, are receiving an epilepsy diagnosis today, who are aware of the ketogenic diet who have access to it who have epileptologists, who are prescribing it in dieticians to work with. It is parent advocates like you that make that change, that make that possible. And so we are all indebted to you and to your family. I'm so happy that it worked for Charlie and that he is living a happy life and just beyond grateful for your time today to share all of it with us.

Jim Abrahams:	28:16	And thank you so much for paying attention to this. I hope it's helpful.
Kelly Cervantes:	28:23	Thank you, Jim, for sharing your son's story with us and thank you for your efforts through the Charlie foundation to advocate for the ketogenic diet, to be better understood and considered as a potential treatment for epilepsy. CURE Epilepsy knows the importance of discovering new treatments. Approximately 30% of people living with epilepsy are unable to control their seizures through current medications. The best hope is finding new epilepsy cures through research. That is why CURE Epilepsy is dedicated to funding patient focused research. We hope you'll help us in our search for cures by visiting cureepilepsy.org/donate. Through research, there is hope. Thank you.
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