Seizing Life, episode 41
Seizure Tracker: Empowering the Community with Data
(Transcript)

Kelly Cervantes:	00:00	Hi, I'm Kelly Cervantes and this is Seizing Life. A biweekly podcast produced by Citizens United for Research in Epilepsy, CURE. Today, I'm excited to welcome Rob Moss to another remotely recorded episode of Seizing Life, as we continue to observe social distancing during the COVID-19 pandemic. Rob's son, Evan, began having seizures as an infant and was eventually diagnosed with tuberous sclerosis, a rare genetic disease that causes non-cancerous tumors to grow in the brain and on other vital organs. The challenges Robin and his wife experienced in communicating with physicians led them to create seizuretracker.com. It's a free online tool that empowers patients to become active leaders in their own treatment, working hand-in-hand with doctors. Today, there are over 34,000 users on seizuretracker.com and the data that is generated is benefiting patients, physicians, and researchers alike. Rob, thank you so much for speaking with us today and joining us on our virtual Zoom set here.
Rob Moss:	01:09	Thank you so much for having me, it's an honor to be able to share our story, both our personal story and our story about Seizure Tracker with your friends and community.
Kelly Cervantes:	01:22	I wanted to learn more about your son, Evan, as it was his experiences and your experiences with him that inspired Seizure Tracker. Speak to us a little bit about him and your experiences with epilepsy.
Rob Moss:	01:37	Our son, Evan, was born with tuberous sclerosis complex. It's a rare genetic disorder that causes tumors to grow throughout multiple organs in your body, and Evan has multiple brain tumors that were there since birth, and has epilepsy and seizures because of those brain tumors. So, we actually were dealing with epilepsy from a very early age and started giving him medications to treat seizures and then really saw that the seizures were getting out of control, and we'd have breakthrough seizures, and increased treatments, and so on. And spent a lot of time just adjusting medications and trying to stop those seizures.
Kelly Cervantes:	02:28	Yeah. I think that's a tune so many of us know far better than we would like to. The constant med adjustment and monitoring the seizures and keeping track of all of that. So, first of all, how is Evan doing today?
Rob Moss:	02:45	Well, thanks for asking. He is doing great. He's a vibrant 16 year old and up until a few months ago was doing wonderful in

school, and he's very social and happy, and we feel very fortunate. I think, when you look around in both the epilepsy community and the tuberous sclerosis community and see families that struggle, as our family does, and then see families that are dealing with other issues associated with epilepsy that are what seem to be much harder to deal with. I think it's an unfortunate situation for anyone to have to deal with seizures and just not fair, but we consider ourselves very lucky and feel fortunate to have such a wonderful child, and son.

Kelly Cervantes: 03:38 I love that. So, explain how Seizure Tracker was born and what exactly is Seizure Tracker, other than what we can tell by the name?

Rob Moss: 03:52 Yeah. So, as I mentioned, Evan's been having seizures since birth and we really went through multiple medications by the time he was four, he had been on, I think, nine medications and we were really struggling to figure out how those medications were impacting both his seizure activity and then other parts of his life. And we'd change a medication and watch for a few months and then have these doctor's appointments to talk about what we thought was happening in between those medication changes. So, around the time Evan was three, his seizures started doubling every month and we really were being aggressive on the medication changes, but didn't have a way to understand objectively what they were doing. So, we sat down and built a website that we could log Evan's seizures into, with the time and date of the seizure, and then graph the seizures against the medications we were taking. So, we-

Kelly Cervantes: 04:57 I'm going to stop you there for a minute because the thing that jumps out to me right there is that, and I think that, I can imagine that many other parents sitting there listening to this, you have your child who you are trying to manage their medications and their appointments and all of this. And you're like, "And then I just built a website." That's superhero status there.

Rob Moss: 05:24 Right. Well, our doctor gave us this single sheet of paper to log 365 days of seizures on, and we'd have these appointments with him, really trying to use that sheet of paper, plus all the notebooks that we had. And we were pretty aggressive about writing down and diarying his seizures, just to understand for ourselves what was going on. And then, it was funny, Lisa and I would sit and argue, sort of argue, but we would disagree on how Evan was doing. And then, the doctor would have to listen to Lisa and I go back and forth on what we think the medication

		impact was happening. And then, it would just seem to be an inefficient use of our time and the doctor's time.
Rob Moss:	06:15	And then, we'd make some subjective decision on the medication we were going to try next, to try to stop the seizures, often with very little success. So, yeah, the going out and building a website, it was interesting because we decided to do this for ourselves and I'd go, and I had a home office at the time, I had my own business. So, I'd go down and try to leverage what I knew about programming websites at the time, and I'd go downstairs and build a piece of the website and I'd bring it up and I say, "Lisa, what do you think about this?" And she'd say, "No, this doesn't work. Go back downstairs."
Rob Moss:	06:53	So, there was a lot of back and forth with understanding what our need was and how we were going to build this for ourselves. So, we actually took it in when it was ready for our doctor to look at and showed him this print out of these graphs it was producing and he asked us to make it public at that point. So, that started a whole new swirl of, well, how do we take what we've built for ourselves and then really turn it into a system that's usable across the epilepsy community?
Brandon Laughli...:	07:31	Hi, this is Brandon from Citizens United for Research in Epilepsy or CURE. Since 1998, CURE has raised more than $70 million to help fund more than 235 research grants in 15 countries around the world. Learn more at cureepilepsy.org. Now back to this episode of Seizing Life.
Kelly Cervantes:	07:51	So, what year was that when Seizure Tracker became a public resource?
Rob Moss:	07:56	Oh, yeah. Well, this is an interesting story. So, I think it was about 2006 when we had that first sit down and showed it to Evan's doctor. We spent about a year adjusting the interface to make it usable for other families and actually launched it from the waiting room at the hospital where Evan was having a three stage focal resection in 2007. So, we had worked on it for about a year making it a usable tool, and then really decided it was ready in 2007 to push out to the public. What was really interesting was they had a waiting room in the hospital, outside of the ICU where Evan was staying, and my brother and I sat down and would code for about the first week that Evan was in the hospital, just tying up some of the loose ends.
Rob Moss:	08:53	And then Lisa pushed it out, I think probably the second or third week that we were in the hospital, to the tuberous sclerosis community forum. And just to make it available to a group that

we knew fairly intimately to get more feedback on. And what was really frightening was, we went to bed one night and the next morning we had 50 people using the website, and the next day 150 people. And we knew at that point that there was definitely a gap for what we had done and produced, knowing what our needs were and then being able to provide it to a much larger community.

Rob Moss: 09:33 So, it really took off in that first period and what was interesting at that point, so we started getting a bunch of feedback from families within the TS community. And then, there were groups, other advocacy groups that really started latching onto it. So, the Dravet families started getting in touch with us and asking for more features and we spent the next year, or two years, really responding to the community and trying to build in new features and tools that we didn't really understand what the need was.

Kelly Cervantes: 10:12 Now. So, it's been 13, 14 years since those original days of coding in your home office and in the ICU waiting room, there are so many more features to this now. It is not just tracking seizures. It is, tracking your ketogenic diet. Talk to us about these additional features that really make this a full program.

Rob Moss: 10:41 Yeah. Thank you. So, for us, it's really interesting because I think we consider it really a community resource and we've set up our development system that we have pretty intimate communications with our user base, and we're able to respond to development requests and feature requests as they come in from our user base, but then also as technology changes. So, just as an example, so, when I mentioned we launched the site, we had never dealt with rescue medications and didn't know that families struggle with the idea of administering these, sometimes on a daily basis. And then understanding what impact those have on seizures as they were happening or possibly preventing seizures. So, it was actually the Dravet community that reached out to us fairly early on and asked for us to include a rescue medication tool.

Rob Moss: 11:37 So, within a couple of weeks, we had really determined by talking to our user base what the need was, and then sitting down with some of our developers and the resources that were in place, really building out a rescue medication tool that fit the needs across the community at this point. So, that's just an example of how we've been able to interact with the epilepsy community and our user base. But then, that's continued over the past 10 years. So, we have been responding to user requests. We added the VNS tool, which lets users record their

VNS settings, the device settings. And then also as a seizure is happening, or outside of a seizure, record when they use their magnet swipe for the VNS.

Rob Moss: 12:36 So, as you mentioned, there's also diet therapy. So, we built, working with the Charlie Foundation, we built a system for users to record the different diets they're on and then see how those diets impact seizures and other aspects of their life. So, really, I think what we've tried to do in the expanse of the tools that are developed, is if there's a gap in need and a user requests something, we explore what the need is. And then we often, the user, or we work with the professional community a lot, that requests tools. We often enlist them as a focus group or adviser to the tool development. So, often they regret actually asking for tools because we really leverage folks who are more intimate with the need, to be able to help us fill that gap and create effective tools.

Kelly Cervantes: 13:40 It's so beautiful that this is borne of the community and by the community. And I love the idea of all of us coming together and which leads me to my next point about, this is a tool, yes, for patients and caregivers, but it's also able to be utilized by clinicians and researchers. So, bringing together all of these people who are all battling epilepsy from different sides, talk to us about how this tool is able to be used by these different communities.

Rob Moss: 14:20 Yeah. So, as you can imagine, the database has grown exponentially in 10 years and we were getting approached by researchers specifically to try to leverage the data, to help understand the natural history of epilepsy, at first. And I remember being at the professional conferences, trying to reach out to doctors and clinicians about this resource and having these researchers come up and go, "Oh my goodness, this is something we should be really looking at leveraging in the community, the research community itself." So, I have to say that our mission was not initially to build out tools to help researchers. Our mission is to empower patients, to have an active dialogue with their clinicians to make better treatment decisions and therapy decisions.

Rob Moss: 15:15 So, that was the initial mission and when we started getting approached by researchers that concerned us, because what we really wanted was a good relationship with our user base, that they had confidence that we were using the tools in the system to meet that gap and that need of improving and empowering patients to communicate with their doctors. So, I think it was in 2015 or '16. We put out a survey to our user base asking if they would want their data used to better understand and help clinicians and researchers understand epilepsy. And 95% of the respondents said they wanted us to use their data. So, at that point, it turned into a mandate for us to create tools that empower researchers to leverage what is our community data and to answer questions that haven't been able to be answered before.

Kelly Cervantes: 16:16 It's so incredible to me that you start this on this micro level of trying to help individual patients communicate better with their doctors, come up with treatment plans that are more effective, but on the macro level, you have the opportunity to put your science forward, to help researchers potentially understand this disease better and have better treatments or potentially cures in the future. And I just think it speaks volumes to the epilepsy community, that 95% were so eager and willing to share that data with the researchers. I know that Seizure Tracker and CURE have worked together in the past, through our Epilepsy Genetics Initiative. Can you talk to me about that a little bit?

Rob Moss: 17:09 Yeah, sure. And that's some of the exciting tools that came out of this change and direction for us, is developing tools for researchers and with the focus of better understanding and leveraging the data. So, one of the things we did was built out a system that users can come into Seizure Tracker and identify other organizations to share their Seizure Tracker data with. So, one of our first data share partners was CURE and with their EGI project, we were able to take Seizure Tracker outcome data, and the patients could come in, identify that they wanted to share their seizure data with CURE, and CURE was able then to combine the Seizure Tracker data with the genetic screening data that they were collecting through EGI. So, this has all progressed from that point, when we first started doing this data share program, we took that interaction and opened that up so institutions or hospitals, that are trying to do small research projects, can actually come to Seizure Tracker very, very rapidly set up a study management tool, to manage small studies within there.

Rob Moss: 18:29 And then we provide a portal for them to come in and help with recruiting into their study, but then also download their data proactively through a user interface, that we provide to them, that they can link into whatever database they have separately. And so, it's a really interesting system to be able to take our Seizure Tracker data and combined it with other registries and other research databases. One of the other things that was fun about changing direction and initiative, was the researchers that were approaching us at some of these professional conferences, one of them was at NIH at the time. And we were able to set up a system where we could de-identify an unlink Seizure Tracker user data, export the full population to outside institutions, so other researchers and hospitals, or organizations.

Rob Moss: 19:31 And they would get a data set that you were unable to identify the folks in the data set. So, we would de-identify it and unlink it. So, after we made the export, then even we couldn't connect the two data sets. So, that's been really fascinating because we've been able to push that full data set out and really learn about the epilepsy community in a much different way, with using what they would call big data to explore different ideas. So, we had multiple publications in collaboration with individual and groups of researchers from outside organizations. So, super fun and kind of cool to see what direction that's going in.

Kelly Cervantes: 20:24 Well, we are beyond grateful for all that you're doing with Seizure Tracker. And I have to ask, how is Evan, how is the rest of your family doing amid COVID? How are you handling this? How is Evan handling these changes? How do you caregive and manage epilepsy during COVID?

Rob Moss: 20:51 I think COVID's going to change all of our lives. I think for people with epilepsy, it's had a very interesting impact. For us, personally, I can give you an example of how we've been having to change our management style. Evan now has status seizures. They happen fairly routinely. So, every two or three weeks we take turns sleeping with Evan, my wife and I, and he has nocturnal seizures that require medication as soon as they start. So, all of them are status. All of them without intervention would last 15 or 20 minutes, if not longer. So, we have a care plan in place where, when Evan starts having a seizure at night, we'll administer a rescue medication to try to stop the seizure as quickly as possible. And if it lasts longer than five minutes, we have to administer another rescue medication, and we call EMS to have them observe or transport if he's still seizing when they show up.

Rob Moss: 22:04 So, most recently, it was quite fascinating, we have our care plan and we make a decision fairly early on whether we're going to transport him or not. If the seizure stops before EMS arrives, we'll let them come in, monitor his vitals for a little while, and then usually turn down transport. But he's been transported multiple times for seizures that are still going on when they show up. And so, for one of his last, more recent seizures, we had administered the first rescue medication, we were waiting. We administered the second rescue medication and called EMS. And as they were en route, Evan stopped seizing. We knew we weren't going to transport him, so we were pleading with them to turn the ambulance around because at this point we've been self isolating for over a month and a half, and having people into our house who are possibly at risk was a concern for us.

Rob Moss: 23:12 Another thing, we did a survey for the Seizure Tracker community last week and realized that ... Or one of the questions was based around this fear of hospitals and 50% of the respondents of that survey said they definitely had a fear of going into the hospital for treatment, inside or outside of seizure activity. So, I think it's changing all of our lives. It's changed how we treat and deal with seizure emergencies. And just something to think about, when we talk to physicians now, who are in hospitals and dealing with patients, I think one of their biggest concerns is that patients are hesitating to come in to the hospital in emergencies. And I think, as a community, we really need to be talking about how safe it is to be going to the hospital, when we should make those decisions, and when we need those sorts of interventions and to be aggressive about those interventions.

Kelly Cervantes: 24:15 I think that's so incredibly valuable and a conversation that everyone needs to have with their doctor. It's, you have your regular care plan, but what is that care plan in the age of COVID? And does it change at all, should it change?

Rob Moss: 24:32 I think, also, inside of the COVID space, now there is a real focus on tele-health and using Seizure Tracker to communicate more effectively with your doctors now, is more important than ever, and hopefully you can integrate the system into how you're currently managing epilepsy and then share more accurate data in a more effective way.

Kelly Cervantes: 25:04 If anyone wants to learn more, seizuretracker.com. Correct?

Rob Moss: 25:09 Yes. So, I'm sorry. You can definitely go to seizuretracker.com to learn more about the system and the tools. There's mobile apps in both iTunes, Google Play, and we have an Amazon Alexa Skill, so you can record your seizures by voice. And I encourage people to go to the website, set up an account, explore the tools. We're really focused on our new initiative of it's not just seizures and understanding things outside of seizures, that are both impacted by lifestyle change and therapy adjustments. And so, I encourage people to go to seizuretracker.com, set up an account, and then definitely explore the mobile apps, which are seizure recorders. They're meant to be used as a seizure is happening, and you can record rescue medications and VNS information as well.

Rob Moss:	26:03	And I do have to mention, we have started a program to integrate Seizure Tracker into the EHR system, and with COVID in place now, it seems much more important. So, we're just weeks away from having our first integration into a nationwide children's hospital. And then, there's four other hospitals that are lined up to integrate and [inaudible 00:26:33]. Seizure Tracker is now available within the Epic App Orchard. So, institutions can go and express interest in those integrations and hopefully this will help both in tele-health and easily communicating this data directly to your clinicians. And really going back to that initial mission of improving that communication set between doctors and patients.
Kelly Cervantes:	26:59	It's amazing. I cannot wait to continue to watch your journey and the Seizure Tracker path. And Rob, we are incredibly grateful to you for having taken the time to chat with us today. Send so much love to the fam and we appreciate your time.
Rob Moss:	27:21	Thank you, Kelly. It's been a pleasure.
Kelly Cervantes:	27:26	Thank you, Rob, for explaining how Seizure Tracker is improving patient care. Your story is truly an inspiring example of how families and patients can make an enormous contribution to the epilepsy community at large. Though, we may be physically separated in this time of social distancing, those of us touched by epilepsy remained together in spirit and purpose. We all want an end to seizures without the side effects of medication. That is CURE's aim and is why we focus on funding epilepsy research. Our dedication to patient-focused research is what will lead us to new discoveries and treatments. We hope you will become a part of our continuous research efforts by visiting cureepilepsy.org/donate. Your support and generosity are greatly appreciated. Thank you.
Brandon Laughli...:	28:15	The opinions expressed in this podcast do not necessarily reflect the views of cure. 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 strongly recommends that care and treatment decisions, related to epilepsy and any other medical condition, be made in consultation with the patient's physician or other qualified healthcare professionals who are familiar with the individual's specific health situation.