

***Seizing Life®*, episode 115**
Teen Tennis Player Remains on Court Despite Seizures and Stigma
Guests: Reid and Ryan Rainwater
(Transcript)

Kelly Cervantes: Hi, I'm Kelly Cervantes, and this is Seizing Life, a biweekly podcast produced by Cure Epilepsy.

This week on Seizing Life, I'm happy to welcome Reid Rainwater and his father, Ryan. Reid is a nationally ranked tennis player and one of the top high school players in Oklahoma. He has experienced seizures since age 14 when in the sudden onset of his epilepsy caused him to leave school and later required him to repeat his entire freshman year. Four years later, the high school sports governing organization in Oklahoma declared Reid ineligible to play tennis in his senior year, resulting in his father, Ryan, taking legal action. Reid and Ryan are here today to tell us about Reid's epilepsy onset and diagnosis and how they fought back against discrimination and stigma. Reid and Ryan, thank you so much for joining us today and sharing your story. To kick things off, Reid, why don't you tell us about how epilepsy first entered your life?

Reid Rainwater: Well, I would say in about my eighth grade year, seventh or eighth grade year, I started noticing I was having these little ticks, like full body jerks, and my mind would go blank for about a second or two and they would be happening all the time. And I didn't really know what they were at first. I just ignored them and kept, I don't know, just pretending they weren't happening, but they were starting to happen more frequently, and then I would start to fall over on some, so then I just thought I would bring it to my parents' attention. And then we started going to the doctors and then that's when things started.

Kelly Cervantes: And Ryan, what do you remember about when he brought this to your attention and how it escalated from there?

Ryan Rainwater: So when he brought that to our attention, we started noticing it more and we started noticing the involuntary jerks. We went to several doctors. We had some conflicting diagnosis. One was a form of Tourettes, another could be epilepsy, and we just let time go on. And it was his freshman year where he had his first grand mal seizure, very long, very violent seizure. And that's where we got the official diagnosis for JME, junior myoclonic epilepsy. And that was when he was 14 years old, just turning 15 his freshman year.

Kelly Cervantes: So that must have been pretty terrifying. Grand mal or tonic-clonic seizures are pretty scary to witness. Reid, what do you remember from that first seizure?

Reid Rainwater: It was about 6:00 in the morning and I decided to get up and play some video games. When I was playing, I was having these little twitches, little jerks like I always do. And then the next thing you know, I'm in a firefighter's hands. So that's pretty much all I remember. I pretty much just remember waking up in an ambulance, to be honest. That's all I can really recollect of that day. That one really messed my head up, to be honest.

Ryan Rainwater: That one was very long. It was very violent. His brother was screaming for me to get upstairs, and when I got upstairs, that's when I saw him in a full grand mal seizure. And I have no idea why I knew to get him on his side, but I did, got him on the ground. We called 911 and luckily the fire department was there within less than five minutes, and he had just stopped seizing probably a minute before they arrived. And he was put in the back of the ambulance pretty quick and he had no clue what was going on.

Kelly Cervantes: So you guys get to the hospital, and how quickly were you able to get that epilepsy diagnosis?

Ryan Rainwater: It was probably a week or two after when we got in front of a neurologist. They did the flashing light test and all those things that they do to test him. And that's when University of Oklahoma officially diagnosed him with JME.

Kelly Cervantes: And Reid, Ryan, what were you told about epilepsy at the time? What information were you given? Were you told about SUDEP?

Reid Rainwater: Honestly, they didn't give a lot of information about really anything. They just said I have epilepsy, and they told me some precautions and then they told me about SUDEP, but they barely went over it. It was just a big vague explanation of everything.

Ryan Rainwater: Very vague. SUDEP was brought up, but nothing in detail. Basically it was be aware of it. And then we started getting on medications to try to keep seizures at bay because once he had that first one, the flood gates opened up for a little bit. He had a total of six or seven more, and the initial medications were not working. If anything, they were making things worse before we finally found Depakote did start keeping his seizures at bay. And they have kept the big ones at bay for four years now.

Kelly Cervantes: It's amazing that you were able to find a medication that could control or prevent those more serious, larger tonic-clonic seizures. But I understand you do still have some of the smaller seizures. What do those look like, feel like? Can someone who's with you tell when you're having one?

Reid Rainwater: If they could tell, they would really have to be paying attention to my eyes and my face. I don't really have that full body jerk anymore. It all happens in my head. It's just a second or two. It doesn't even feel like I'm awake. It's just like two seconds go by and I wasn't even there. Yeah, honestly, can't really tell that it happened.

Kelly Cervantes: Have they been able to do any tests that have given you a cause for the epilepsy?

Reid Rainwater: No.

- Ryan Rainwater: No. I think that's the most frustrating part from his mom and I's standpoint is the neurologists really don't know. They're still in the dark of the why this happened. He did have a traumatic birth and that's the one thing that we can point to is the birth was pretty rough, but other than that, perfectly healthy those first 13, 14 years, and they came with a vengeance.
- Kelly Cervantes: Explosive onset, right? It is the right term for it. It's always so frustrating and it's shocking to me that more people don't understand, I guess, perhaps outside of the epilepsy community, but it is two-thirds of the people who are diagnosed don't know why they're having seizures. That's a majority. It's such a large portion of this community that has no answers. And I think that that can be so frustrating, as you said, and isolating and it can be exceedingly hard to treat something when you don't know what is causing it. What was your experience like seeing providers? Did you get second opinions? How has your treatment journey played out?
- Reid Rainwater: Honestly, the doctors, I just think are a joke. They don't help with anything. We flew to John Hopkins to see some really good epileptic doctor, and we were in and out in 10 minutes. It's with every single doctor.
- Ryan Rainwater: Yeah, we got second and third and fourth opinions. We went everywhere. We went to Dallas, several places, obviously University of Oklahoma. We went to John Hopkins. And as Reid is saying, it was very frustrating because I think they don't know, and maybe they see so many that they're just immune to the feeling of it. But we found the whole process to be very frustrating, not getting a lot of new information. The place that we go to locally, we never saw the doctor. We only saw the PA. So we never once even spoke to the actual neurologist here locally in Oklahoma City. Now we did in John Hopkins, and we did in Dallas at the places that we went. But it's always about trying new medications, that's it. Try this one, try this one. And they all have the same side effects as the one before, except this one maybe makes you less angry, but we just never found anyone that was truly willing to sit down with him and try to understand it and try to help.
- Kelly Cervantes: I'm so sorry that that has been your experience and I wish that that wasn't something that I have heard over and over again from other patients and families. I think there's 101 reasons why that is the experience, but there's no excuse really that justifies it.
- Brandon: 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 25 years Cure Epilepsy has been committed to inspiring hope and delivering impact by 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: Reid, I wonder outside of tennis, which we'll talk about in just a minute, how have your seizures impacted your social life and your education?

Reid Rainwater: I would say my social life has been fine, been good. I made my main best friends after the fact of having seizures. Maybe it's made me a little more isolated. I don't want to go out as much or do certain things. But I would say my social life is good.

Kelly Cervantes: And what about school and education? Do you have any sort of accommodations? Do you notice times in school, whether it's the epilepsy or the medications that you know feel impacted?

Reid Rainwater: Yeah, it's definitely impacted my school a lot. I can barely do any math without having a seizure. Math just messes with my head that it's weird. And honestly, it's the same with writing. If I'm writing for too long and I'm really focusing on something, it just messes in my head and I can't do it.

Ryan Rainwater: Yeah, he missed an entire semester of his freshman year basically because he was either recovering from a grand mal seizure or... Literally we had five or six different trips to the hospital. And as one neurologist told him, "Well, listen, you just ran a marathon in four minutes. It's going to take you a week to two weeks to recover." That semester that he missed, he did. It looked like almost like he had a concussion for months. It was very scary and just heartbreaking as a parent. But like I said, we did find something that has finally kept them at bay. We hit the reset button his freshman year, and since then, his grades have been great. The Edmond North schools do give him accommodations, but this past year he's done virtual, which it has seemed to help where he has a little bit more flex time.

Kelly Cervantes: That's great. And I do understand that you also ended up switching schools too. What was the reason for that?

Reid Rainwater: Honestly, I didn't want to be in the same place where I was having seizures. I wasn't like having seizures there. I just wanted to switch up everything. I don't know, I just felt everything was just wrong that whole year and it just felt wrong and I just needed to change.

Ryan Rainwater: It was a traumatic year, and that school was a private school and did not have the IEP accommodations that a public school does, and Edmond North was very accommodating. It's a great school. It's obviously the district we live in, and it has been a very beneficial move, in my opinion.

Kelly Cervantes: I'm glad you were able to find a school where you felt comfortable and maybe had a little less trauma associated with it. Okay, so now I want to dive into tennis. You are a nationally ranked player, one of the top high school tennis players in Oklahoma, which is amazing. Congratulations. I can only imagine how much hard work you have put in to get to that level. Now, you lost a year of high school tennis because of the seizures and trying to find a medication that worked. And I understand that you were trying to apply for a hardship waiver, which would allow you an additional year of high school tennis eligibility since

you did have to repeat a year of school. Explain to us that process and what happened.

Ryan Rainwater: Yeah, basically we just needed to document why he needed that extra year, which we did. We explained in detail his freshman year, basically missing that entire second semester, not competing on the tennis team that year. He didn't play one single point for that school, and we basically just hit the reset button. So the hardship waiver just basically goes through those questions of why you need it, and we were initially denied that hardship waiver.

Kelly Cervantes: Now, did you have any idea that you were going to be denied, or did you think that this was sort of a given?

Ryan Rainwater: We kind of thought it would be a-

Reid Rainwater: Oh, it was a given.

Ryan Rainwater: We thought it would be a given just because the facts are right there. It was very clear what happened to him. We weren't trying to get an extra year to get a better scholarship or do anything that would cause a red flag. I mean, it was very, very straightforward. The people that we talked to that have done this before, they're like, "Yeah, this is a slam dunk. It's no big deal."

Kelly Cervantes: So what was the reason given for Reid's waiver being denied?

Reid Rainwater: I can read it right here. They said-

Ryan Rainwater: The documentation.

Reid Rainwater: The documentation submitted did not demonstrate a circumstance beyond the control of the student. So they're saying epilepsy, I can control that, and that's something I can control like an injury.

Ryan Rainwater: Yeah, the documentation submitted did not demonstrate a circumstance beyond the control of the student, which prevented Reid from making normal academic progress.

Kelly Cervantes: Reid, isn't that amazing? You can control your epilepsy. Did you not know that?

Reid Rainwater: Yeah, I just thought that was hilarious.

Kelly Cervantes: At some point you have to laugh. I'm sure you were very, very angry. But it's just the most ludicrous thing I've ever heard. I would've loved to have controlled my daughter's epilepsy or known that she could just magically control it on her own.

Ryan Rainwater: Yes, mom and I went from zero to a hundred in anger very quickly when we read this, and we immediately got on the phone to find an attorney and we immediately fought back.

Kelly Cervantes: Good for you. And what did that process look like?

Ryan Rainwater: I was recommended to an attorney locally who has about 15 years experience with litigation with the OSSAA, the Oklahoma Secondary School Activities Association. He's very involved. He knows the ins and outs, and we had an initial call with him. He asked me for the letter and he said he would call me 5:00 that afternoon after he reviewed it. And I think I got a call 20 seconds after I sent him this letter, and he reviewed it and he was appalled and immediately got us involved with a young attorney here in town, Hannah Whitten, who is very familiar with the epilepsy world, actually lost a brother to epilepsy. So she took an immediate interest in this case, and they really got to work. Literally the day that we met through email and on phone calls, they got to work.

Kelly Cervantes: That's incredible and good for you for fighting this stigma and going to the lengths that you needed to because that's not always an easy step to take. I do want to be clear. It's my understanding, Reid, you have been medically cleared to play. It is not like there is any concern or risk or liability. Everyone says you're good to go.

Reid Rainwater: Yeah, a hundred percent. Every doctor's told me that.

Kelly Cervantes: Yeah. So what was the end result? Is the case still active? I'm not up on legal words.

Reid Rainwater: So we got a news channel to come interview me, and pretty much right after OSSAA heard that I had an interview, they said, "You can play." We sent them an email saying, "We'll air this on Wednesday if you don't give us an answer about playing on Monday." And then they immediately let me play.

Ryan Rainwater: It was a quick turnaround. This was Hannah's suggestion that we go live with it with the news. And we did. We just basically said the story can be killed Monday at midnight or we're running with it. And like Reid said, it was Monday afternoon that we got word that he is now eligible and is the case still open? Not for that. And then now all of a sudden they're asking if he's made practice enough. So they're still trying their witch hunt on Reid for some reason, but we're fighting that as well. And yes, he's made practice enough just to be very, very clear. He has made the majority of the practices. They're really trying to make it as hard as they can on him.

Kelly Cervantes: I'm so sorry to hear that, but I am thrilled to hear that the attorney's work paid off and that you are currently playing. I wonder, Reid, what advice would you give to other young people who are faced with an epilepsy diagnosis and are also facing stigma like this and misunderstanding? It's just a total lack of

awareness or knowledge about how epilepsy can impact a person or not impact them as the case may be.

Reid Rainwater: For me, I've tried to let it impact me as little as possible. Obviously the first year I had seizures, I let it impact me a lot. I let it just control my thoughts and it put me in a bad spot. But once I just started just living without caring, to be honest, everything started to fall into place. I would just tell people that if you have a seizure, it's not the end of the world. I know it's terrible. It's like the worst thing ever, but you got to keep living because other people are going through things that are terrible too. People are getting diagnosed with cancer and stuff like that. If you have a seizure, you just got to keep living. That's all you can do.

Kelly Cervantes: Very true sentiments all the way through. Parenting is difficult. Parenting a teenager is another level. Parenting a teenager with epilepsy is beyond that. It's not easy. What advice do you give to a parent who has a child who's diagnosed, but also who's up against an organization or a situation that is telling them that they can't do something that they can?

Ryan Rainwater: The first part of the question, yes, it is very difficult to watch your child suffer. It's the hardest thing that we have gone through and that we continue to go through because yes, he's done an amazing job of making his grades. Tennis is on a whole nother level, in my opinion, what he's able to do, and he's still having what he calls these head glitches. It is amazing. But the darker side to epilepsy, the harder side that the people don't see, and my wife and I, we see it and we see what he's going through, but we don't feel what he's going through because it's his journey. You've got to have empathy and you have to try to be patient the best you can because it is very easy to get angry. It is very easy to lash out.

But to these parents, you've got to be patient. And then I would seek out some of the social media sites. There's great chat rooms where other parents are going through it and they're sharing their stories and you realize that you're not alone. I know my wife is on several of them. I know it's helped her to talk about it, and she's met new people through it.

And in terms of the stigma and facing issues of discrimination, I would say number one thing is do exactly what we did and immediately fight. Get an attorney referred to you, call the Epilepsy Foundation, call Cure Epilepsy. There are attorneys out there willing to help. We found too, that immediately jumped on it, and especially Hannah, we can't say enough about her. She knew so much about epilepsy and she cares about these kids, and she cares about these issues as much as anyone as I've ever met. She was 10 times more helpful than any neurologist that we've ever met. So I would just say in those circumstances, you have got to fight because the stigma's not going away right now. And you've got to be willing to stand for what's right.

Kelly Cervantes: Yeah, absolutely. So Reid, you are currently playing tennis. How is your season going and does your epilepsy affect your game at all?

Reid Rainwater: Yes, it does actually. But first of all, the season's going good. The first three tournaments back, we've won two, so that's pretty good. Yeah, I'm playing good. I've won my tournaments. But epilepsy definitely does affect me while I'm playing. And it only started recently for some reason, literally this past year, past six months, actually, it's really weird. But I'll be playing and I'll just have a head glitch or something like that and the ball will go right by me. And it's just really weird. I'm having a seizure while I'm playing, and that's never really happened to me before, but it's been happening pretty consistent now. But hey, I'm not going to let it make me stop or anything. It's just annoying.

Ryan Rainwater: We did up his medication just a little bit to try to help this, and we're watching it closely, but he is playing great, and he says these are happening, you can't really notice. But he is letting us know about it. So we're watching it closely. But in terms of his play, it's top level.

Kelly Cervantes: That's amazing that you are able to play through it and that you're able to play at such a high level despite having a seizure while you're playing. It's incredible and I think a remarkable story to hopefully inspire others out there who are in a similar position to not let their seizures stop them, of course, within the guidelines of medical care and proper rest and all of the things that we know are important. So, Reid, what's next for your tennis career?

Reid Rainwater: Well, I have committed to a school MSU Denver, and I'll be moving there this summer.

Kelly Cervantes: Congratulations.

Reid Rainwater: Thank you.

Kelly Cervantes: Well, I know that all of us here at Cure Epilepsy will be cheering you on and you'll have to keep us posted and updated. In the meantime, we are so grateful to both of you for sharing your story, for fighting against stigma and for keeping going because goodness, is it important. So I just thank you both so very, very much, and I can't wait to see what's in store for you, Reid.

Reid Rainwater: Thank you.

Ryan Rainwater: Thank you.

Kelly Cervantes: Thank you Reid and Ryan for sharing your epilepsy journey with us and for raising awareness about epilepsy stigma and discrimination. We wish Reid continued success as he begins his college tennis career next year. Cure Epilepsy has been funding patient-focused epilepsy research for 25 years. During that time, we have made significant discoveries and advances in epilepsy diagnosis and treatment, but there is still work to be done to find a cure for epilepsy. If you would like to help us achieve our goal of a world without epilepsy, please

visit cureepilepsy.org/donate. Cure Epilepsy, inspiring hope and delivering impact. Thank you.

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