

Seizing Life, episode 101
Remembering a Brother Lost to SUDEP and Finding Hope in Community
Guest: Hannah Whitten
(Transcript)

Kelly Cervantes:	00:00	Hi. I'm Kelly Cervantes and this is Seizing Life, a biweekly podcast produced by CURE Epilepsy. Today I'm happy to welcome Hannah Whitten to the podcast. Hannah's brother, Dylan, was diagnosed with epilepsy at the age of two. As his younger sister, Hannah grew up with epilepsy and seizures as a constant part of her life, often acting as a caregiver to Dylan.
	00:35	Watching her brother struggle with epilepsy shaped Hannah's experience greatly. When Dylan passed away from Sudden Unexpected Death in Epilepsy, or SUDEP, in 2017, Hannah became involved in the epilepsy community as a member of several non-profit organizations and is a CURE Epilepsy board member.
	00:56	Hannah is here today to share her experience growing up alongside a sibling with epilepsy and to discuss how that perspective informs her work within the epilepsy community. Hannah, thank you so much for joining us today. I have been so looking forward to this conversation. To start, why don't you tell us a little bit about your brother? What was he like and what was your brother-sister relationship like?
Hannah Whitten:	01:23	Thank you, Kelly, for having me. I'm so excited to be here. Dylan is my older brother by five years. I grew up in a pretty big family, the youngest of five siblings. And Dylan was five years older than me, so he was the closest in age to me, and that made us extremely close.
Kelly Cervantes:	01:43	When was Dylan diagnosed with epilepsy, and when did you become aware of what epilepsy was and seizures?
Hannah Whitten:	01:53	Dylan was diagnosed with epilepsy at two years old, so for as long as I had been alive Dylan had epilepsy. I don't necessarily remember how epilepsy was explained to me by my parents or Dylan. But I do remember learning about the risks, such as Dylan couldn't swim alone or all the other things that have to do around epilepsy. I remember being scared of losing him.
Kelly Cervantes:	02:21	That's a tough thing to be aware of as a young child, these incredible life and death risks. I wonder if you could tell me what was Dylan's attitude toward his epilepsy?
Hannah Whitten:	02:37	Well, surprisingly Dylan was pretty positive about his epilepsy. I tell this story because it's one of my favorites. I think it's pretty emblematic of the kind of person Dylan was. But we attempted

a brain surgery when Dylan was 17. They had cut into his skull and realized that where his epilepsy was located was too integral or important to him to remove.

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| | 03:04 | My family was discussing how we were going to cheer him up because we thought this was such a devastating loss, and Dylan was the positive one. He was trying to cheer up my whole family and saying how grateful he was to be alive and how lucky he was. I think that just shows the kind of person that he was. |
| Kelly Cervantes: | 03:25 | While you were telling that story I couldn't help but notice your use of we. We decided for Dylan to have brain surgery. We were trying to cheer him up. Clearly, even though there was a five-year age difference, you were very involved in his care. I wonder what that looked like on a day-to-day basis for you. |
| Hannah Whitten: | 03:46 | Well, my parents got divorced when I was pretty young, so the only person Dylan saw on a day-to-day basis was me, and that made us very close. But it also made me pretty aware of his epilepsy and how best to stay on track with his epilepsy treatment plan. But I was absolutely aware of his epilepsy, and I think it made us a lot closer as a team. |
| Kelly Cervantes: | 04:14 | I can only imagine how close you must have come being that constant in each other's life and being the one who was always there for him. How did Dylan's epilepsy impact him as he was growing up? Did it impact him socially? Did it impact him in school? Did he have an IEP or anything like that? |
| Hannah Whitten: | 04:36 | It impacted every aspect of Dylan's life growing up. I remember that Dylan was bullied by his peers for having epilepsy and just being different. I know kids are mean, boys are mean, and that was definitely something that he struggled with. Additionally, we were consistently switching out the medications he was on. But he was consistently on a cocktail of drugs that had their own side effects. Dylan would have trouble sleeping, or sleep too much and have trouble getting up. I mean I'm sure you're aware, but the multitude of side effects of these epilepsy drugs impacted pretty much every aspect of Dylan's life. |
| Kelly Cervantes: | 05:16 | Yeah, sometimes the side effects are worse than the seizures themselves. Was he able to get accommodations in school? |
| Hannah Whitten: | 05:25 | When Dylan was going to school, our experience was that we had a hard time even finding educators who were aware of epilepsy and how to handle that in a classroom experience. I do remember Dylan having a seizure when he was in middle |

school. He had hit his head on the desk repeatedly and we were wondering, "How could that happen when there's a teacher there?" But the teacher was also frozen and wasn't sure how to handle the situation. I don't think it was made available to us to have an option to have an individualized study plan or school plan.

06:03 I think we were just hoping for an environment that was capable of taking care of him and his epilepsy. But I think that there have been positive movement and changes towards that position. Recently, Oklahoma passed the Seizure-Safe bill, which works towards educating schools and educators about how to handle epilepsy and what's the best way to approach having a student in your classroom with epilepsy. So I do think that there are positive changes there. But no, Dylan never had any accommodations in school.

Kelly Cervantes: 06:36 You know, 25 years is a long time to cover, but I wonder if you can give us sort of a brief overview of his treatment journey. What type of treatments did he try? Did you ever find the cause of his epilepsy?

Hannah Whitten: 06:54 Well, the first doctor that my family had seen about Dylan's epilepsy had told us that if we did not find the right combination of drugs and achieve seizure control within the first year that we likely never would. That ended up to be true for us. Dylan consistently switched out his medications once he got used to them or we realized they weren't working.

07:18 Dylan had a vagus nerve stimulator implanted in his chest, and while that did initially curb his seizures, it didn't have the kind of impact that we had hoped for him. As I had mentioned earlier, we tried an unsuccessful brain surgery. We didn't ever really achieve seizure control in the way that people define it. But before he died it was the closest we had ever gotten to seizure control.

Kelly Cervantes: 07:46 Which makes that that much more devastating I'm sure, to have seen him at his best. Did you ever learn a cause of what was behind his epilepsy? Was there any epilepsy in the family?

Hannah Whitten: 08:02 Yes. Our aunt had very mild epilepsy, nothing like Dylan's, and they were completely different experiences. But yes, it did run in the family. And we really were told by doctors that there were a lot of things Dylan would never be able to do, but Dylan ended up proving those doctors wrong. Dylan went to college, and before he passed away he was living by himself which took

us a long time to achieve. He was working a full-time job, and so he defied all the odds towards the end.

- Kelly Cervantes: 08:43 Was Dylan open about his epilepsy? I mean I imagine to achieve all of those things between going to college or just making it through high school with as challenging as it sounds like his epilepsy was, was he forced to be open about it or did he choose to hide it?
- Hannah Whitten: 09:03 I think he was forced to be open about it. Anyone who was close to Dylan knew he had epilepsy for a variety of reasons. Right? I mean anyone who was close to him we talked about the vagus nerve stimulator, about the battery. We discussed just the various different risks. And Dylan was very blessed to have a huge network. You know, it takes a village. My family is a pretty big family. They're very supportive. And Dylan's best friend growing up, Tyler, ended up living with him throughout college, and so we had a really good network of people to support Dylan.
- Kelly Cervantes: 09:42 Was your family open? Did they talk about it and advocate for him in public during his life?
- Hannah Whitten: 09:52 Absolutely. Hindsight is 20/20. Being involved with all these different organizations that focus on epilepsy now, I wish we had gotten to know that greater community sooner. But we didn't, and Oklahoma was pretty isolating in terms of our epilepsy journey. So yes, we advocated for Dylan, but I don't think we knew the right networks and resources in terms of advocacy.
- 10:18 But it was absolutely not something that we hid about Dylan. I do know that there are different consequences about being open with your epilepsy in terms of losing your license and being discriminated against at work. We were aware of those things, but for us, hiding Dylan's epilepsy just wasn't an option.
- Brandon: 10:40 Hi, this is Brandon from CURE Epilepsy. Did you know that one in 26 Americans will develop epilepsy in their lifetime? For more than 20 years CURE Epilepsy has funded cutting-edge, patient-focused research. Learn more about our mission to end epilepsy at cureepilepsy.org. Now back to Seizing Life.
- Kelly Cervantes: 11:01 You mentioned that being in Oklahoma could feel isolating for someone with epilepsy. I wonder if you can dive into that a little bit more.

Hannah Whitten:	11:11	Well, I think having epilepsy by itself is pretty isolating. There is a huge stigma around epilepsy and it's hard to get past that and share it. But also living in a state where we didn't meet another family who dealt with epilepsy until Dylan was in his mid 20s and we met the Stone family. But that within itself makes it feel like you are living on an island. You don't know anyone else who suffers from this. You don't know anyone else who has to find a way to live their life through this, and it was extremely isolating to us.
Kelly Cervantes:	11:51	How did you first get involved within the epilepsy community? You mentioned meeting the Stone family.
Hannah Whitten:	11:58	Yes. Well, Renzi and Lee Anne Stone are just amazing people. I know Renzi sat on the board, so Kelly you're familiar with Renzi. My brother in the last year of his life really wanted to get involved with epilepsy. I think it had just been brought to his attention that there was a national platform for this, and my dad introduced him to Renzi and Lee Anne Stone.
	12:23	They lost their son to epilepsy, and Dylan, and Renzi, and Lee Anne, just became fast friends. They really gave Dylan an opportunity to see the epilepsy community and what awesome work they do through that. Through being involved with ISF, Dylan actually got to attend a CURE Epilepsy event. It was pretty life-changing for him to see the incredible group of stakeholders working together to find a cure.
Kelly Cervantes:	12:52	You mentioned that Dylan was able to go away to college, which is an incredible feat for anyone who is living with active seizures. You said that he had a friend that went with him. However, how did having epilepsy affect his college life as a student? Were there certain parameters that he had to live within?
Hannah Whitten:	13:13	Absolutely. As anyone who has loved someone with epilepsy, they understand that it makes huge life sacrifices. After seeing so many things that Dylan had to give up because of epilepsy, college was something that my family was pretty determined to make work. We were so grateful that Dylan had his best friend who was fully aware of his epilepsy and knew how to monitor his epilepsy. So that was a huge blessing to us because what college kid wants to live with their parents?
Kelly Cervantes:	13:50	[inaudible 00:13:52].

Hannah Whitten:	13:53	But I mean yeah, there are certain aspects of being a college student with epilepsy that just make your experience different than everyone else's. I think the common 18 year old is having to argue about getting an alcoholic beverage, but we were arguing about Dylan drinking coffee, so [inaudible 00:14:13].
Kelly Cervantes:	14:13	He didn't want to give up that coffee? Huh?
Hannah Whitten:	14:17	Yeah. It was hard for him. You know, it's just a different experience.
Kelly Cervantes:	14:19	Yeah. I wouldn't want to either. I didn't want to give it up when I was pregnant either. That one's tough. Now, if you are comfortable doing so, can you tell us some of the circumstances around your brother's passing from SUDEP?
Hannah Whitten:	14:38	Yes. Well, before my brother passed away, we were in the best place we had ever been in terms of his epilepsy. They were countless doctors who told us all the things Dylan couldn't do. That Dylan couldn't get his license. That Dylan would never be able to live alone. Dylan couldn't go to college or work a full-time job. But he ended up proving them wrong. And it was really exciting for us to see Dylan finally live alone. Gosh, that was such a huge step for us. There was a lot of fear there too. Just like going to college there's risks anytime there's independence. But his quality of life mattered to everyone and we wanted him to be as independent as possible.
	15:22	So he was working a full-time job as a LiDAR specialist at an oil company. He was driving to work every day and living alone for the first time in his life. Things were looking good. He had switched neurologists cause his neurologist had retired, so that was a change for us. But in terms of seizure control, it was the best that it had ever been. Then on August 27th, 2017, my brother passed away. It was explained to us as though his heart just stopped. I think it was pretty devastating, because if you love someone with epilepsy you know all the ways that they could pass away, the thousands and thousands of risks, all the myriad of ways. But we had never heard of SUDEP, and so that was a shock to us when he passed away.
Kelly Cervantes:	16:18	I'm so so sorry for your loss. I know that there's nothing that you can say that makes it better, nor am I in any position to try and make it better. But it really super sucks, and so so sorry. You mentioned that you had never heard of SUDEP before. It had never been brought up by any of his doctors? None of you were aware of it?

Hannah Whitten:	16:48	No, and Dylan had so many family members very active in his epilepsy care, and for none of us to have heard of SUDEP. I mean no one in my family, not my parents, not my sister who is a doctor, especially not me. So I think it definitely came as a surprise to everyone, especially because he was doing the best he'd ever been. I try to find hope in his story and the fact that he was able to prove people wrong. That if doctors have told you as a person who lives with epilepsy that there are limitations, that you can defy those odds and it's possible. But it's also devastating to lose your best friend at just 25 years old.
Kelly Cervantes:	17:34	Yeah. Well, I certainly think that determination runs pretty strongly in your family genetics. We've done several shows around SUDEP. One piece that sort of continuously comes up when someone passes from SUDEP is with the medical examiner and getting SUDEP listed as the cause of death. Which is important from a research perspective because A, we need to know how common it is.
	18:08	But it also, unfortunately the more common it is, the more money can be made available for research to prevent it from happening to further patients. I wonder if you had something similar with the medical examiner having SUDEP listed, and you mentioned that you hadn't known of SUDEP before. How did you learn about SUDEP? Was that when you first heard of it?
Hannah Whitten:	18:41	I recognize that that's an issue, but for us it was listed on his death certificate. In fact, that's how we found out about SUDEP. When someone you love dies, you're desperate for answers about why. And we had discussed all the vastly different ways that Dylan could be injured, or hurt, or possibly die from epilepsy-related causes. But we had never heard of Sudden Unexpected Death in Epilepsy. So that was the first time that we had ever seen SUDEP, was actually on his death certificate.
Kelly Cervantes:	19:17	I know that shortly before Dylan passed, he had attended a CURE Epilepsy benefit and had been greatly moved by his experience there. Can you tell us about that and how that has led you to become involved with CURE Epilepsy as one of our newest board members who we are very excited and fortunate to have.
Hannah Whitten:	19:45	Thank you, Kelly. Well, as I had mentioned earlier, the Stones we're very great to Dylan and really introduced him to the national platform of epilepsy causes. They brought Dylan to the CURE event in 2017. And man, he was just blown away by the group of people, and the work that CURE does, and just how

many people actually care about curing epilepsy really shook him. And he made a promise to be involved with CURE and the fight against epilepsy for the rest of his life. Sadly, he passed away very shortly after that event. I was pretty lost in my grief after my brother passed away, as anyone who's lost someone that they love. It's pretty isolating.

20:38 The Stones recognized that in me and really threw me life vest because they got me involved with the Isaiah Stone Foundation, which is in honor of their son. Through that work I got to meet the amazing Beth Dean, and you Kelly, and just the amazing people who are involved with CURE, and CURE's become like a second family to me. And even though Dylan can't fulfill the promise that he made, I hope that I can carry on that promise in his name, and through research there really is hope. I hope that we can find a cure for epilepsy.

Kelly Cervantes: 21:20 Amen sister. I often say that, and in fact it was David Axelrod who first said it to Miguel and I that, "So sorry that you're a part of this club, but we're so happy to have you." There is this community and this family like you mentioned. It's a crappy club, but my goodness are the members some of the most amazing humans that you will meet. As a board member, as a part of this community and a leader in this community now, what do you hope? What are your goals? What do you hope to achieve as you take on your brother's mantle?

Hannah Whitten: 22:02 Well, first and foremost, as a new board member, I think the most important thing I would like to be a part of is finding a cure for epilepsy. Being involved in the conversations where the funding should go in terms of the most important research is such a privilege. I'm so excited to be a part of finding a cure for epilepsy, but also battling the stigma around epilepsy is very important to me and something I would like to make a positive change.

Kelly Cervantes: 22:31 Hannah, you are a force. You have your brother's determination to be sure, and we are so grateful to you for sharing your story, for sharing Dylan's story with us today. Thank you so so much and wishing you all the best.

Hannah Whitten: 22:51 Thank you so much Kelly.

Kelly Cervantes: 22:56 Thank you, Hannah, for sharing your experiences and perspective with us. And thank you for honoring your brother's memory through your continued efforts within the epilepsy community. CURE Epilepsy has been a leader in SUDEP research, advocating for a better understanding of the issue,

and driving the research forward. The guidelines that doctors use today to help patients reduce the risk of SUDEP are an outgrowth of this research. We hope you will help us in our mission to better understand SUDEP and support CURE Epilepsy by visiting cureepilepsy.org/donate. Through research, there is hope. Thank you.

Legal Disclaimer: 23:42

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