

Seizing Life, episode 66
Epilepsy
Education and Seizure Safety in Schools
(Transcript)

Kelly Cervantes:	<u>00:00</u>	Hi, I'm Kelly Cervantes, and this is Seizing Life, a bi-weekly podcast produced by CURE Epilepsy.
Kelly Cervantes:	<u>00:18</u>	Today, I'm excited to welcome Colleen Quinn and her son, Paul St. Pierre to the podcast. Paul was diagnosed with epilepsy in November 2018. As he struggled to gain seizure control and dealt with the side effects of medication, Paul and his mother were dismayed at the lack of awareness and understanding of epilepsy within their school system. Spurred by this, Colleen and Paul set out to get a law passed, making epilepsy first aid training mandatory for New Jersey teachers. They are here today to tell us about Paul's diagnosis, his experiences with epilepsy, and how it drove them to be epilepsy advocates.
Kelly Cervantes:	<u>00:54</u>	Colleen, Paul, thank you so much for joining us today to chat. I would love to know how epilepsy first entered your lives.
Paul St. Pierre:	<u>01:04</u>	When I first experienced epilepsy with the seizures, I knew nothing. I knew nothing of what epilepsy was. I knew-
Colleen Quinn:	<u>01:15</u>	You weren't sure what was happening.
Paul St. Pierre:	<u>01:17</u>	Yeah. And-
Kelly Cervantes:	<u>01:18</u>	And what was happening?
Paul St. Pierre:	<u>01:20</u>	First, it started as an eye twitch, and then it started... Or then it progressed to a arm and leg moving kind of thing.
Colleen Quinn:	<u>01:33</u>	In school, it was happening on a very high frequency and he complained to me about his eyes and he had had three prior eye surgeries. So I took him to his eye surgeon, got his eyes checked, because I wasn't familiar with a seizure that looked anything like that. But I was describing it as like a seizure in his eye. So it took a while for us to get a diagnosis. Unfortunately, the types of seizures had to progress and change for us actually to get the diagnosis.
Kelly Cervantes:	<u>02:06</u>	How did you get the diagnosis? You take him to the eye doctor, did the eye doctor refer you at some point to a neurologist? What was your diagnostic journey?
Colleen Quinn:	<u>02:17</u>	I first saw the eye twitch that he was describing, and I drove him to the emergency room at a pretty well-known hospital in Philadelphia. And they told me that it was panic attack and

stress, and to basically go home and get some counseling. And then it continued to happen. I took him to my pediatrician. He thought it was possibly a tick from ADD medication. So it really took it to happen in his office for him to realize the severity of it. And then that's when we got referrals for MRIs and EEGs.

- Kelly Cervantes: 03:00 So you go in for the MRI and the EEG. Were you thinking epilepsy? Had anyone mentioned that to you as a possibility?
- Colleen Quinn: 03:08 To me, yes. And I really didn't discuss with Paul epilepsy or anything else at that point because we weren't sure what it was. Our family doctor was scared that actually it was a brain tumor. So I was familiar with epilepsy. I work with kids with developmental disabilities. By that point, I think I knew, but I didn't know the cause.
- Kelly Cervantes: 03:32 And so you get your diagnosis, I'm assuming in the hospital, when you went in for those tests. How was it explained to you about epilepsy and how they were going to treat it?
- Colleen Quinn: 03:47 I guess it was basically explained by, "Here's the medicine. It works in most cases. It's epilepsy." And I think at that point, I was so thrilled that it wasn't what people had been mentioning before, a brain tumor or something of that nature. So I was just so happy to have medicine. I didn't ask a lot of questions. I was just thrilled by that alone, because by that point he was having like five and six seizures in a day and they had progressed to a level of unawareness complex, partial unawareness, and they were pretty scary.
- Kelly Cervantes: 04:29 Absolutely, I'm sure. Was the medicine effective?
- Paul St. Pierre: 04:33 The first medicine we tried, the side effects were not really that good. Sunburn was a big one because one time I went to the beach and I went to my mom, because we were down the shore, and I was red.
- Colleen Quinn: 04:50 And then the brain fog.
- Paul St. Pierre: 04:51 The brain fog was also one of them.
- Colleen Quinn: 04:54 We were very fortunate though. It held off seizures with minimal breakthroughs for a year and four months actually.
- Kelly Cervantes: 05:04 But at a significant cost.

Colleen Quinn:	<u>05:07</u>	True. Absolutely true, but it did hold them off and we're thankful for that. Unfortunately, he began to have breakthrough seizures this February and on a weekly basis that were pretty significant and there was a choking incident where he turned blue. So we're actually just starting a new medication and he's had a few, I think the last one was three weeks ago today. So we're hoping that we're on a better path with this new med.
Kelly Cervantes:	<u>05:41</u>	Well, crossing all my fingers and toes that that works out because-
Colleen Quinn:	<u>05:45</u>	Thank you.
Kelly Cervantes:	<u>05:46</u>	... my goodness, the pharmaceutical roulette is certainly a tricky game to play.
Kelly Cervantes:	<u>05:51</u>	You're talking about this brain fog and you're having seizures in school. How did that affect you in school both academically and socially?
Paul St. Pierre:	<u>06:02</u>	My closest friends didn't really know what to do besides one of them, because I had a seizure in front of him in his backyard. And from the training that my mom taught him, he knew what to do. But in school, I had a lot of them, the teachers knew nothing about them and I got bullied for it.
Kelly Cervantes:	<u>06:23</u>	I'm sorry to hear that. What would the teachers do when you had a seizure in school?
Paul St. Pierre:	<u>06:28</u>	The first thing was to be calm.
Colleen Quinn:	<u>06:31</u>	And have you walked to the nurse.
Paul St. Pierre:	<u>06:33</u>	Yeah.
Kelly Cervantes:	<u>06:34</u>	By yourself?
Colleen Quinn:	<u>06:35</u>	Initially.
Kelly Cervantes:	<u>06:37</u>	I can understand why there was certainly some concern for your safety in a school environment, which really catapulted you guys into advocacy so, so early and quickly after your diagnosis. Talk to us about Paul's Law and what motivated you to make such incredible change in your state of New Jersey. And also my current home state, I might add.

Colleen Quinn:	<u>07:11</u>	I had met a woman through Facebook. There's so many good connections that have come out of social media with epilepsy for us. I met a woman who was working on seizure safe schools in Texas. She hadn't passed it yet. And she suggested, "Well, why don't you do it in New Jersey?" And I was like, "I don't know. That's a pretty big undertaking." I looked at the numbers and I went to Paul and I said, "Well, Paul, you're 12, we need to talk about this. What are your thoughts? There's 12,000 kids in New Jersey that have epilepsy. What are your thoughts? What do you want to do?" And you can tell Kelly what you decided.
Paul St. Pierre:	<u>07:55</u>	She asked me, "What do you think we should do?" And I said, "Let's do it because I like trying new things and this is big."
Kelly Cervantes:	<u>08:06</u>	It's very big, and a lot to take on, especially when you're being bullied in school. And in order to get this law passed, you have to be pretty public about your diagnosis. That takes a lot of bravery.
Colleen Quinn:	<u>08:20</u>	Yeah.
Paul St. Pierre:	<u>08:21</u>	Yeah.
Colleen Quinn:	<u>08:21</u>	He's very courageous. I'm very proud of him, but he wanted to stand up for all the kids who don't have a voice or weren't comfortable standing up.
Kelly Cervantes:	<u>08:32</u>	It just seems so like such an enormous task to take on. What steps did you take? How did you even get the ball rolling to get this bill passed in the state of New Jersey?
Colleen Quinn:	<u>08:49</u>	At this point, Paul was obviously struggling emotionally and I actually... We have a local weather station that comes out of Philadelphia. It's actually a country music station and he loves country music and they have a weather child on the stage each and every day. So I applied for Paul to be the weather child, and they contacted me ironically and said, "He's a little too old for that." And I said, "Well, I'm trying to lift his spirits. Here's his story." And they said, "Bring him into our station and he can talk about epilepsy awareness." Well, we had called Senator Beach and requested a meeting. Well, that day Paul was on the radio. Senator Beach's daughter must be a country music fan. So she heard it on the radio and called her dad and said, "You better help this little boy to make a law." So by the time we got there with the Texas law, Sam's Law in hand, and the Lyndsey Crunk Act in hand from Kentucky, he said, "Paul, you don't have to sell

me. It's a go." So we were very fortunate. We've been very fortunate.

- Brandon: 09:59 Hi, this is Brandon from CURE Epilepsy. Since 1998, CURE Epilepsy has raised over \$78 million to fund more than 260 epilepsy research projects in 16 countries around the world. Learn what you can do to support epilepsy research by going to cureepilepsy.org. Now back to Seizing Life.
- Kelly Cervantes: 10:21 So you have your state Senator on your side, helping you. What did you do next? What is that process like?
- Colleen Quinn: 10:30 Again, we were blessed. Senator Beach is a former teacher and he had a student have a seizure. So we couldn't have gotten luckier. We started our Facebook page, Paul's Purple Warriors. We reached out to other people who were working on the bill or who had passed it, Cyndi Crunk in Kentucky, Shari Dudo in Texas, and just got advice and they sort of helped us along. We grew the page. I had parents knocking on my door that lived in my town, thanking me and hugging me that I never met in my life because their kids had epilepsy.
- Kelly Cervantes: 11:07 It is such an important piece of security too, to know that you are sending your child to school and that the professionals in that building will know what to do when your child has a seizure. To that end, can you explain specifically what is in the law and what it entails?
- Paul St. Pierre: 11:27 The law is pretty much about training teachers, bus aides-
- Colleen Quinn: 11:36 Administrators.
- Paul St. Pierre: 11:37 Administrators-
- Colleen Quinn: 11:38 All school personnel, really.
- Paul St. Pierre: 11:40 Yeah. The training to know what to do when a child specifically with epilepsy has a seizure.
- Colleen Quinn: 11:50 And also, the course which can be taken by Epilepsy Services of New Jersey or the Epilepsy Foundation of America also teaches recognition of seizures because what Paul was describing as an eye twitch could have been diagnosed sooner when it was happening in school. And maybe that's because there was more stress and the workload or whatever versus at home. So, the hope is that that training will help teachers not just to know

how to respond, but to be able to identify different types of seizures. And it also includes a seizure action plan.

- Kelly Cervantes: 12:34 Colleen, explain to me. I understand what a seizure action plan is certainly in a home. What does that look like in a school setting and who receives that action plan in the school?
- Colleen Quinn: 12:47 In New Jersey, the way it's written in our law is it's a health plan. So it's written specifically by the child's epileptologist or neurologist and the parents. And then it's given to the school nurse and disseminated specifically, individually for each child because not every child has the same rescue meds, not every child you would call an ambulance at the same time. Some kids need to lay down. And so it's individualized to the student with epilepsy.
- Kelly Cervantes: 13:16 I'd love to hear in your own words, from both of you, why this law is so important. I think on a very base level, most people can understand just sort of the fear of generally not sending your kid to school and the teacher doesn't know what to do. But I think that there's so much more to it than that that people probably don't understand goes along with a child having a seizure in school. I'd love to sort of hear your thoughts on why this is so important.
- Paul St. Pierre: 13:48 This law is really important to me because if this law wasn't a thing, I wouldn't really feel safe going to school, being around my friends, because if I have a seizure and no one knows what to do, I'm not going to be safe.
- Colleen Quinn: 14:12 Right. And there's 12,000 kids in the state of New Jersey.
- Kelly Cervantes: 14:15 I think that there's even more to it than that. I mean, you start looking in the public schools in particular and they're cutting the school nurse out of the school. There isn't necessarily a school nurse there every single day. So you can't expect a child to only have a seizure on the day that the school nurse is there and can help with that. Or the trauma of if a child were to have a tonic clonic seizure or something that looks evidently scarier. And a teacher calls an ambulance when perhaps that's not necessary as part of the seizure action plan and sort of the trauma that goes along with that and the embarrassment for the child to have to... And the disruption for the rest of the classmates. For the ambulance to be called in, or a parent meeting to always be within a short drive of the school and how that affects their family economically from a job standpoint.

Kelly Cervantes:	<u>15:14</u>	I think there's just so many reasons why this is so necessary to be passed in all states. And so I'm just so thrilled that you guys really stepped up and made this happen in New Jersey. You've really gone beyond just trying to make this a law in New Jersey and you're trying to help people get these passed all over the country. Talk to us about that.
Colleen Quinn:	<u>15:40</u>	I was very blessed to have Shari's help in Texas and Cindy's help in Kentucky. Once we passed, we had met a couple moms in Virginia, Christie and Rowena, and they were reaching out to Shari and I and wanted to work on it. So we would talk to them on the phone. And then we started to get... I would get inboxes from people in different states and then so would Shari in Texas. So finally I said, "Can we just put all these people in one place so we can all share information?" Like it easier and teamwork, this whole thing. So that's when we started the national page, National Epilepsy Advocates for Seizure Safe Schools. There's so many great people in there, advocating in their states. So it's been a great journey to be a part of and to help them and give back the help that we had.
Kelly Cervantes:	<u>16:39</u>	Absolutely. And that is a Facebook page. I want you to just say the name of it again for anyone who might be looking for more information.
Colleen Quinn:	<u>16:47</u>	National Epilepsy Advocates for Seizure Safe Schools.
Kelly Cervantes:	<u>16:51</u>	Amazing. Mean, I think it's so great to see the parents coming together and rallying and sharing this information and getting this passed. I don't think that people realize that they can get involved in their own state. I know personally I was asked... I was raised in Nebraska, and Nebraska currently has a bill up and is trying to get one passed. I got alerted to it and I got to write a written testimony and share my written testimony to try and help get this bill passed. And so I think there's so many ways that people can get involved. They don't always have to be the one who gets the ball rolling, but they can still be a part of the process. And thank goodness, there are people like the two of you who are willing to get that ball pushed up the hill.
Colleen Quinn:	<u>17:40</u>	Thank you.
Kelly Cervantes:	<u>17:41</u>	It wasn't enough for the two of you to get this incredible bill passed in New Jersey and to help people all over the country, try and get bills passed in their own states. You continue to raise money for epilepsy awareness. Talk to us about your organization and some of the exciting events that you have coming up.

Colleen Quinn:	<u>18:03</u>	So we formed Paul's Purple Warriors to get support for Paul's Law initially. And then we began to have people reach out, "How can we help? What can we do?" So we are partnering with Epilepsy Services of New Jersey, which is part of the American Epilepsy Alliance, to do an event called Seize the Wave. This one's near and dear to my heart, because this is something kids with epilepsy may be fearful to do, but with the right safeguards in place, we have doctors, we have nurses, we have volunteers. We're going to be able to have 30 kids with epilepsy and their families come to the beach for the day, have lunch, and the kids will be able to serve. So we're super excited. They're going to have their individual trainers to teach them and help them. So we're pretty excited about that one.
Kelly Cervantes:	<u>19:00</u>	That is wild and so much fun. And you're right, it is something that a kid with epilepsy isn't normally going to be able to do. There's so much concern around water safety, but you've created this safe environment and given them the opportunity for an experience they wouldn't have otherwise had. It's really incredible.
Colleen Quinn:	<u>19:19</u>	And we have a guest star coming, who is a surfer, who actually has epilepsy, who lives in California. I reached out to him, he was kind enough to come. He works for the company, Patagonia. They donated shirts. So everyone will be able to have an amazing time.
Kelly Cervantes:	<u>19:37</u>	Oh my gosh, that's incredible.
Colleen Quinn:	<u>19:40</u>	And then in September, we are partnering with the Epilepsy Foundation of Eastern Pennsylvania, along with Sail For Epilepsy, who is Phil Haydon from the Massachusetts area. And he is bringing his sailboat down. He sails for epilepsy awareness and we're doing a fund event with them in Pennsylvania on the Delaware River in September.
Kelly Cervantes:	<u>20:07</u>	I love it. Well, you have to keep me posted on when all these events are happening.
Colleen Quinn:	<u>20:11</u>	Absolutely.
Kelly Cervantes:	<u>20:12</u>	As advocates, you have done so much in such a short period of time. What do you wish that people understood about epilepsy?
Colleen Quinn:	<u>20:22</u>	I wish they understood how to help when they see someone have a seizure. Instead of being fearful, I wish they knew how to

help. I think that's the most important thing or the biggest gift the general public could give to the community of people with epilepsy.

- Kelly Cervantes: 20:39 Absolutely. I feel like there is a general consensus that knowing... CPR is a generally good thing for people to know, but I think that seizure awareness and seizure first aid should be right up there with CPR. And with help from the two of you, certainly in the public school systems and beyond, I think that we are inching closer to making that happen. I am just so grateful to both of you for your advocacy, for speaking with us today. I think your bravery and your compassion for others speaks volumes. So thank you so, so much.
- Colleen Quinn: 21:22 Thank you.
- Paul St. Pierre: 21:22 Thank you.
- Kelly Cervantes: 21:27 Thank you, Colleen and Paul for sharing your story with us and for transforming your personal challenges into positive change for so many others with epilepsy. As Colleen and Paul's story demonstrates, it only takes one or two voices to bring awareness and make significant change within the epilepsy community. One way that you can bring about change is to support CURE Epilepsy's mission to fund epilepsy research. There are a number of ways you can help us realize our goal of a world without epilepsy. To find out how you can use your voice to promote and support epilepsy research, please visit cureepilepsy.org/get-involved. Thank you.
- Brandon: 22:15 The opinions expressed in this podcast do not necessarily reflect the views of CURE Epilepsy. 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 Epilepsy strongly recommends that care and treatment decisions related to epilepsy and any other medical conditions be made in consultation with the patient's physician or other qualified healthcare professionals who are familiar with the individual specific health situation.