Seizing Life, episode 128

NYC Marathoner Achieves Seizure Control and Runs for Epilepsy Research

Guest: Peter Burpee

(Transcript)

Kelly Cervantes: Hi, I'm Kelly Cervantes and this is Seizing Life, a biweekly podcast produced by CURE Epilepsy. Today, I'm happy to welcome Peter Burpee to the podcast. Peter's first experience with epilepsy occurred around the age of 10 when he was diagnosed with absence seizures. Following a period of seizure freedom, Peter's seizures returned in a sudden and rapid onset when he was in high school. He's here today to tell us about both experiences, how he's been able to achieve seizure control, and why he's running in the upcoming New York City Marathon to raise funds for CURE Epilepsy. Peter, thank you so much for joining us today. Why don't you start off by telling us a little bit about how epilepsy first entered your life?

Peter Burpee: Yeah, absolutely. Thank you so much for having me. I think my journey with epilepsy first kind of began when I was in fourth grade, kind of started having absence seizures then. My teachers noticed that I was zoning off a little bit in class and kind of brought it to the attention of my parents saying, "Just want you guys to be aware of this." And my parents didn't really think a whole lot about it. I was doing well in the school, very active in extracurriculars.

And my parents first noticed it when I was out during a football game one day and the whole rest of the game was going on on one side of the field and I was just off in the corner dozing off. I think this was the first time my parents were like, "Hey, this is a little more serious, we need to get this checked out," and made an appointment with a child neurologist and he ran an EEG that found there was some abnormal brain activity and just kind of started the... He found that I had absence seizure. And the doctor wasn't too worried about it, he said that "two-thirds of kids grow out of these," and put me on some medications that worked great and I was seizure-free, and eventually kind of weaned off the medicine.

Kelly Cervantes: And so what were you told at that time? So fourth grade, you're 9, 10 years old, you are able to know that something is not quite right. Do you remember how it was explained to you or what you were told about it? Were you nervous?

Peter Burpee: I don't think it really registered for me. My parents weren't super worried about it and were just happy that there was a plan and at least somewhat of a solution that was working at the time. And they were just kind of glad that I was healthy and if this was the worst of it, they weren't too worried about it and saw that it wasn't really affecting my day-to-day life too much and was able to continue on with school and sports and social life. I don't think it really hit me just because I was so young.

Kelly Cervantes: So how long were you having the absence seizures before they were controlled?

Peter Burpee: I think it was probably a couple of months. I think that the doctor did a great job of getting a handle on things and started the medicine pretty quick and the medicine was obviously working. So that was obviously fourth grade and I think that the absence seizure kind of came and went as far as middle school and eventually weaned off the medicine kind of shortly before high school started.

Kelly Cervantes: So then you had this period of seizure freedom, but it didn't last, unfortunately. Tell us about how and when those seizures returned.

Peter Burpee: Yeah, so going into high school seizure-free, that was great. Didn't really think about epilepsy at all, it was just kind of in the past and I was all excited to start high school, start driving, that sort of thing, all the excitement that comes with high school. And I was on a service trip my sophomore year summer down in the jungles of Panama. We were building a sports court for a remote village and I was coming back, my brother was with me as well as probably 20 some classmates and a couple of teachers, and we'd stopped at a rest stop and that was my first time having a grand mal seizure.

My teachers didn't know what it was, my brother didn't know what it was and he thought I was actually having an allergic reaction, and so he went and... As a smart brother would do, he grabbed an EpiPen and stabbed at my thigh and they took me to the hospital and no one was really sure what happened. And so they put me on some meds just to... enough so I could get home on the plane. And the plan was just kind of like figure it out when I got home, but they just wanted to make sure that I could get home safely.

Kelly Cervantes: I can't imagine how terrifying that must have been for you and for your family. Do you remember much from that time? And what were you told when you got back home?

Peter Burpee: I know my parents were pretty scared just because... I mean, as a parent you would probably understand. My dad was sitting at work and he got a phone call that came through from Panama and he, I think kind of assumed that something bad had happened. And I think his biggest worry was just like, can we get him home? When can we get him home? And fortunately, it was the end of the trip, so it was pretty quick time period as far as when the seizure happened and getting me home. I don't remember anything from that day, I just kind of remember limping my way through the airport because my leg was so sore. But when I got home, I think that there was a little bit of a grace period as far as when I got home and when we could see the doctor get in touch with a neurologist.

And so that Saturday when I'd gotten home, I was headed to Vancouver, Washington for a lacrosse trip. My brother was in the backseat with me and I had actually had another seizure on the way to the lacrosse trip and my parents told me that my brother looked around to dad, "It's happening again, the same thing." And so my dad was like, "This is obviously not an allergic reaction." So they pulled off on the highway and we were close to a hospital, so they brought me to the hospital and they put me on some medication there, some short-term medication, and they recommended we go see the neurologist obviously. So we got in touch with the neurologist and that was kind of when we realized things were a little bit more serious.

Kelly Cervantes: Now, had anyone sort of put the connection together yet that your epilepsy had returned in a different form and how long did it take for that connection to be made?

Peter Burpee: I think it was pretty quick because I assume doctors must have asked like, "Hey, does he have any history of epilepsy?" And obviously, absence seizures are quite a bit different than grand mal seizures, so that connection was definitely made pretty quickly. And when he was able to actually get in touch with the childhood neurologist that I'd seen for my absence seizures, he ran an EEG and just started pumping me full of medicine. I think I was up to probably about 14 pills a day and the seizures still were not stopping. I was having three to four or five of them a day and having them all over the place, whether I was in the classroom, in the lunchroom, on planes, at the airport, at home, it was just nonstop. And my parents were getting pretty frustrated because obviously the medicine and 14 pills a day weren't helping. And that was kind of when they realized, "Hey, this needs to go a different direction. I think we need to visit a new neurologist or just kind of change approaches here."

Kelly Cervantes: Time to get a second opinion. And I do want to get to that because I am a huge proponent and advocate for getting additional opinions, second, third, fourth opinions. It is so valuable. But I want to pause for a minute because you're talking about having all of these seizures in the classroom, on an airplane, you're a junior in high school, how was this impacting you academically, socially? Clearly, you were involved in athletics and all these different activities. How did you cope with that?

Peter Burpee: I think it was hard being that young and having to go through it. I mean especially in high school, you want to be as involved as you can and just want to be having fun with your friends and doing well in school and just being there for all of it because it's your formative years. And it was hard getting my driver's license taken away and not being able to play lacrosse for a season and having to miss quite a bit of school. And I think it just weighs on you in a number of ways. So just academically, it led to spending a lot of time before and after school getting caught up. And fortunately, I was able to have very supportive teachers and just the whole kind of administration was there for me in whatever I needed. And so they were willing to put in that extra time because they saw how much I valued it.

So fortunately my grades didn't drop as much or I was able to stay up to date with some accommodations. Sports, wasn't able to play, for obvious reasons. That was very frustrating because sports were a huge part of my life growing up and all you want to do is be active and be out there with your friends and playing sports that you love and just kind of have that taken away in the blink of an eye is... I don't know, it just felt like life-changing at that moment. And socially, I think I just kind of felt frustrated because I felt like I had to rely on my twin brother to drive me around since I couldn't drive or have friends always pick me up or just kind of felt like I was always somewhat of a liability to them. And they always just had to constantly worry about, oh, is he going to have another seizure? Is it going to happen? And not even if, it's just more of a matter of when is it going to happen again. So it was just a very frustrating time period.

Kelly Cervantes: It's pretty heavy stuff for a 16-year-old to be weighing on a daily basis.

Brandon: Hi, this is Brandon from CURE Epilepsy. Have you or a loved one been recently diagnosed with epilepsy? Are you looking for more information about epilepsy and available treatment options? Go to cureepilepsy.org/for-patients to get resources and information about epilepsy. Now, back to Seizing Life.

Kelly Cervantes: Obviously, this wasn't something that you could keep from your teachers or your friends because of how visible your seizures were. You mentioned that your teachers were supportive. How did your friends react?

Peter Burpee: Again, I was very lucky to have very supportive friends and just a surrounding community around me. So I think that they were all just very supportive and wanted to do anything that they could to help, but I think a lot of them were just kind of confused and didn't exactly understand the whole scope of the picture. And this was a lot of their first times experiencing epilepsy firsthand. And I think they were probably feeling a little bit of fright and just a little bit of confusion, but they just wanted to be around and wanted to be as supportive as possible.

Kelly Cervantes: That's so important for other young people with epilepsy to hear because you didn't have a choice in keeping this from the people that you are around every day. And you were still supported by your teachers, by your friends, by your community, and so I want to make sure that that message gets heard. I want to jump now to your parents coming to the conclusion that it was time for a second opinion. Talk to us about that journey.

Peter Burpee: Yeah, absolutely. As the grand mals kind of progressed and we continued to meet with the original childhood neurologist, it was just kind of like a natural progression where he was like, "I think it's worth seeking a second opinion." And that combined with my parents' frustrations, it was pretty natural. But during one of the periods where I was having quite a few seizures, we called the paramedics. And I think this was after the third or fourth one of the day, and they said, "I think it's time for you to check him into a hospital." And so went up to the hospital, they checked me in overnight, hooked me up to an EEG machine, and I actually had a grand mal while I was hooked up. So they kind of obviously analyze and investigate kind of their findings.

And when I got connected to the new neurologist, he went back and looked at that and also had me come in and do an MRI in the middle of the night. And so combine those two findings, he was able to localize the, I guess area of my brain and figure out the trigger point of where those seizures came from, and he was able to just figure out down to a T what was causing them. And from there, just put me on the exact kind of concoction of medicine that has been what I've been taking for the last seven, eight years and have been seizure-free since. So been very fortunate to have that quick finding, quick transition to a new neurologist.

Kelly Cervantes: It sounds like this second neurologist that you saw was definitely an epileptologist and that they were able to read all of these scans, but I wonder if that first neurologist that you were seeing, were they also an epileptologist?

Peter Burpee: I don't remember off the top of my head. From what my parents say though, I don't think he specialized in grand mals. So it kind of makes sense, I guess, why I was driven down a different path.

Kelly Cervantes: Yeah, it's such an important distinction that I don't think a lot of people are aware of that not every neurologist is an epileptologist, but every epileptologist is a neurologist. And when you are facing these pervasive seizures, it really is important to see those specialists. And it doesn't mean that you are abandoning your original neurologist, it just means that you need more specialized care and you need someone who has been trained in epilepsy specifically. So I'm just so grateful that you were able to get that care and to see an epileptologist that could treat you and knew exactly what medications were going to help you. So how old were you when you got control of those tonic-clonic seizures?

Peter Burpee: I think I was about 17 or 18, so probably spring of junior year of high school.

Kelly Cervantes: Okay. So you got to go into your senior year with the seizures under control. That must have been such a relief. And as you're starting to look at colleges, what was that process like? Because I'm sure... You had gotten control of these seizures, but you and your family are very well aware that they can return. How did you navigate that transition to college?

Peter Burpee: Definitely stressful, but I think a lot of it came down to kind of having mature discussions together as well as with the neurologist and just kind of seeing what everyone was comfortable with. And he was confident in what was going on in our plan, and fortunately, that didn't come with too much restrictions. And I ended up going to college about furthest place away from home. So he was comfortable with me going to college 3000 miles away from home. And I think that if he was comfortable with it, my parents were confident as well. And I think that it was just important to have those mature discussions, and it was just... Looking back on the whole thing, I'm just so fortunate to have been in that place and be able to have that help at such an early stage and such a formative stage.

Kelly Cervantes: So you go to college, you're on these medications, you've had this terrible school year of seizures. Did you notice whether the history of the seizures or the medications that any of it affected your schoolwork in college? I mean you weren't having seizures, so now it was your choice to tell your teachers, to tell your roommates, to tell your friends. So I guess two parts here. A, did you tell them, and B, did you see any lasting effects academically?

Peter Burpee: Yeah, I mean to answer part A, I was very transparent with my roommate from day one. It's not something I want to hide just because I think it's important for him to know what would be going on potentially, worst-case scenario. And it's part of me, it's who I am, it's something that I want those around me to know and understand what goes on when it happens, and it's not beneficial to anyone to hide it. And then as far as professors go, they knew as well. I wanted to just be open and upfront with them as far as what happens. And was fortunate to have some test accommodations in college as well, which was very helpful. And my professors only wanted the best for me, which was great too. So they were very supportive. And I think being at a smaller school like Lehigh with 15 to 20 kids per class, it was just very great to be in those smaller classes and develop those personal relationships. And that's why I felt like it was important for me to be transparent with my professors.

Kelly Cervantes: Yeah, absolutely. And did you notice any sort of... You talked that you had accommodations, and if you're open to sharing, I wonder what those accommodations were. And also I think it's important for people to understand that even if you're not actively having seizures, how epilepsy can still affect you academically, and why you needed those accommodations.

Peter Burpee: Yeah, absolutely. I think just after going through all those seizures, it definitely takes a toll on your body, takes a toll on your head, and it just kind of felt like it took a little bit longer for my brain to process some things and just had time and a half on exams and found that to be super helpful. And as far as just academics in general, I think that having it in high school and going through all the seizures in high school, it kind of taught me from that younger age that it's just going to take a little bit more work for me than others potentially for me to get where I want to be.

And so I wasn't afraid to go in early or stay late or spend extra time with the professors on things that may take others less time to understand, may take me a little bit longer, and just to learn not to get frustrated with that because all of it is out of my control. I can't control and I'm going to have a seizure. So just try not to put too much blame or guilt on it and just understand that this is life and this is how maybe... It just may take a little bit more time.

Kelly Cervantes: Yeah, absolutely. You graduated from college and now you are living and working in New York City. How are you managing your epilepsy now? I know that you're not actively having seizures, but a lot goes into... It's more than just taking some pills every day to make sure that they don't return, you have to take care of yourself. So Peter, how have you managed your epilepsy now as you are working and living independently?

Peter Burpee: Yeah. I think a lot of it kind of comes down to balance for me. One of the things that I've always prioritized is sleep. And so trying to get at least six hours, which obviously isn't necessarily doable every night. But trying to do that and combine that with eating healthier, having a healthy diet, and then combining that with getting just exercise in general, which has been great, just learning to appreciate running, which I know we'll get to later. So just kind of combining a healthy diet with exercise and sleep. It's just all kind of a balanced scale for me and it's kind of allowed me to figure out what's important in my life and what I want to prioritize. And I think just keeping that all in mind, just day in and day out because like you said, it is more than just taking a couple of pills a day.

Kelly Cervantes: I have to say, I'm so impressed with your confidence and your awareness around your diagnosis, and your openness to talking about it. Just so valuable and so important. I wonder, is it something that you still talk about now with friends? Is it something that you disclose to your employers? How have you managed those conversations?

Peter Burpee: I think with friends, at that level, it definitely came up when I started college, and you kind of develop friendships, and I was very fortunate to find a close group knit of friends very early on freshman year. So that discussion obviously kind of happens naturally and just like I said with my roommate, I wanted to be very transparent and open with them about it. And they were all very understanding and a lot of them hadn't had firsthand experience with epilepsy, so you had to educate them a little bit. But they were all very supportive and wanted to be as helpful as possible, whether that was getting my parents' phone numbers or getting a doctor's phone number, just understanding what to do in a worst-case scenario situation.

But as far as letting fellow employees know, I think that's just kind of come up naturally. It was never something that I wanted to hide nor immediately lead with when I guess interviewing for jobs or just working at my current job. And it just kind of came up naturally in a couple of the different settings. And again, haven't tried to force it either way, haven't tried to hide it. And people understand at this point in their lives that people deal with different things, whether it's different health scenarios or different just baggage in general. And I think that that's been great because people at work have been very understanding. And I think when you share something traumatic that you've gone through, it makes them want to connect on a deeper level. And so they'll sometimes share something that they've gone through, whether it's related or not. And like I said, it's just kind come up naturally.

Kelly Cervantes: I love that. One of the biggest challenges that I know epilepsy patients have as they transition to adulthood is a lot of times they have to find a new epileptologist, whether that's because they've moved 3000 miles away from home or just transitioning from a pediatric to an adult provider. How was that transition for you?

Peter Burpee: I think I was, again, very fortunate to have it be a pretty natural transition. One thing that we found was the whole epilepsy network as well as just child neurologists in general, it was a very tight-knit group. A lot of doctors, if they don't know them on a personal level, they've heard of them or they've done different studies with them or know them through some other connection. And so I was able to get connected with a great group of doctors back here in the NYU Langone network and just was a pretty natural connection from my childhood neurologist to a couple of names back in the NYU Langone network and have been able to develop pretty quick relationships with them back here and have been able to get along well and kind of be on the same page as far as getting a plan going in my mid-twenties here. And I have been very fortunate to just kind of luck out with that because it's not the case for a lot of people. So I have been very, very lucky.

Kelly Cervantes: You mentioned the tight-knit community of epileptologists and you are so right. And I think it's somewhat bittersweet. It works to our advantage certainly when we're trying to connect with new doctors. And then on the flip side of that, I think it's often because we don't have enough epileptologists out there. We need so, so many more. Super exciting. I'm just so excited to talk to you about this because I am just in awe. You are going to be running in the New York City Marathon on November 5th for CURE Epilepsy. Talk to us about how you came to decide to run in the marathon because I still cannot even wrap my head around 26.2 miles, and why you chose to run for CURE Epilepsy.

Peter Burpee: Yeah, absolutely. Believe it or not, I have never been a huge fan of running, was never very good at it. I did cross country my freshman year of high school and part of that was my parents kind of forced me to do it to meet some people, but was awful at it. Didn't like it, have never loved running long distances, but for some odd reason, I've always just had running a marathon on my bucket list. And so my first year after moving to New York, I went and saw the New York Marathon on the day it was happening and was just in awe of the people running it. I was in awe of how much New York City came out and supported those group of runners. And it's just kind of a pretty amazing day to experience in general in New York. And I just remember thinking, I was like, "I want to do that. As much as I hate running, this is something I want to do."

So obviously the New York Marathon has a pretty competitive lottery to get into. So then I found out that you could run for different charities and different charity sponsor groups of runners. And I was like, "Gosh, that seems like a cool way." What do I care about? What am I passionate about? And it's like, well, I had a cool or pretty amazing journey with epilepsy and I'm so fortunate to be here and where I am now. And I was like, "I wonder if there's any epilepsy foundations." And so I kind of did some Googling around, did some research, and I saw that CURE had sent a group the previous year. And so I started googling around a little bit more.

And I love what CURE stands for. I love that it aligns with what my values align with, and it's just something that I can relate to and something that I'm passionate about. And no matter how grueling those 26.2 miles are, it's nothing compared to what kids and families have to go through as far as having seizures and grand mals and the number of other horrifying things that happen with epilepsy. But I'm just so excited to be able to run for CURE and be able to raise money for research and just different awareness for it. And it's getting closer to race day, so I'm getting very excited.

Kelly Cervantes: Well, we are so honored to have you run for CURE Epilepsy. I will be there in New York City cheering you on with the CURE Epilepsy team. And it is, it's just such an incredible day in New York, and I'm beyond impressed that you'll be out there participating and running. It's incredible. Peter, thank you so much for talking with us today, for sharing your story, and for running 26.2 miles for CURE Epilepsy on November 5th. Cannot wait to cheer you on.

Peter Burpee: Thank you so much for having me.

Kelly Cervantes: Thank you, Peter, for sharing your epilepsy journey with us, and best of luck in the New York City Marathon on November 5th. As Peter noted, he's been fortunate to achieve seizure control twice, but one-third of people living with epilepsy are not able to control their seizures with current medications. And many of those who do achieve control, experience challenging side effects from the medications, that's why CURE Epilepsy is dedicated to patient-focused epilepsy research. For 25 years, we funded research aimed at better therapies and ultimately cures 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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