Brandon Laughlin: Hello everyone. Thank you for joining us today on the second day of our Unite to CURE Epilepsy event. Today we are uniting to share and I am joined by three very important members of the CURE Epilepsy community and they're joining us from all around the country. We have Peter Burpee, Channing Seideman, and Daniel Allbeck, who will be sharing their experiences of living with epilepsy.

As you all may know, everyone's epilepsy story is very different. So we have asked that these three to join us in a conversation where others can learn and ask questions. Now this will be a hundred percent audience-driven event, so please do submit any questions you have in the chat and I'll do my best to address as many of these as possible until we run out of time or until we just run out of questions.

Now, before we get to some of those questions that were submitted ahead of time, I'm going to ask each of our panelists to introduce themselves, tell us a little bit about where they're from, share a bit about their epilepsy diagnosis, and also tell us how they've been involved with the CURE Epilepsy organization.

So we are going to go with the sun here and start with the East Coast and move down to the West Coast. So Peter, I'm going to go ahead and start with you.

Peter Burpee: Perfect. Hello everyone. My name is Peter Burpee. Recently graduated from Lehigh University back in 2021 and moved to Manhattan right after. My epilepsy journey began when I was around 10 or 11. Started with petit mal seizures and slowly grew to grand mal seizures. Was fortunate enough to get linked up with some incredible doctors up at OHSU in Portland, Oregon where I'm from, and I got involved with CURE Epilepsy very recently as I will be running the New York Marathon with them. So happy to share my journey, answer any questions and be as much help as I can.

Brandon Laughlin: Thank you, Peter. All right, next we'll go ahead and move to Channing.

Channing Seideman: Hi, my name is Channing Seideman and I am in Milford, Ohio. I was initially diagnosed with epilepsy when I was 10 with a later diagnosis of juvenile myoclonic epilepsy and I got involved with CURE Epilepsy as a fundraiser for their CURE Epilepsy Champions Program and we're excited for our fifth annual event this November.

Brandon Laughlin: Last but not least to Daniel.

Daniel Allbeck: Hi, I'm Daniel Allbeck. I'm from Riverside, California, which is about our east of LA. My epilepsy journey started when I was 22. Up until then, I didn't have any epilepsy or any signs. I didn't really know what even epilepsy was besides what the general public might, the assumptions that they make of them. But then when I was 22, I had a grand mal seizure and that's when it all started. It just came out of nowhere and they still don't even know why or how it happened, but they started at grand mal. I'm not actually super familiar with all the terminology, but I know that I have both focal and generalized episodes and they can go from a simple as just like little light flickering in my eye to a complete tonic-clonic seizure. But in 2001, I mean 2021, I had brain surgery and I haven't had a gram mal since then, but I still do have my absent seizures.

Brandon Laughlin: Thank you. Thank you all three of you for sharing and we're going to hear a lot more about each one of your epilepsy stories as we get to some questions. We did have a good many questions actually submitted in advance, so we've got a nice starting point. I do want to remind our audience that everyone's experience with epilepsy is different. So while our panelists have agreed to answer their questions, this obviously should not ever replace any sort of guidance or anything from your medical care team.

I'm going to go ahead and start and open this question up to everyone because I want today's event and presentation to be more of a conversation. We actually had somebody write in that they have a nonverbal special needs son who developed later-onset epilepsy about two years ago, and he cannot tell them how he feels and they want to know if there's any signs that they should look out for so that they know what it feels like prior to a seizure. They've also noted that he's fallen and really done a number on his forehead a couple of times, so they really want to know what that experience has been like for you guys before you have a seizure. So anybody go ahead and just go ahead and open it up and I'll open this up to you all.

Daniel Allbeck: I'll start, but like you said, everybody experiences it differently. So I would imagine that Peter and Channing didn't go through exactly the same thing that I do, but when I first got epilepsy, they call it auras when you start feeling it come on. I was not a person who got auras, but now I do. The people that observe me, having them what they see, because when you're having it, you don't usually know that you're actually having it. But from the outside perspective, what they see is I start to look confused. I just stare off into space. When they see that, they immediately grab me and tell me to sit. Grab me, you shouldn't shouldn't grab, but gently suggest "Daniel, you should sit." And sometimes I'm pretty combative about it, but you can see it in my eyes, like "He's not there." You might ask me a question, but I'll respond and my answer won't make much sense. Sometimes I'll lose track of time.

If the person is asking, what should I look for to see if my son's about to have a seizure? I would say absent eyes, confused and answers that are... They don't make sense, but he's not-

Channing Seideman: Oh, go ahead.

Daniel Allbeck: Sorry. [inaudible 00:06:02]. No, it's okay. I'm pretty much done.

Channing Seideman: Like Daniel, I don't get auras but over time I have learned my body and that off feeling it gets before a seizure, but it is not necessarily an aura where you have, whatever that aura may be I know it can be different for everybody.

Daniel Allbeck: And other people with migraines talk about the aura the same way that they'll talk about it with epilepsy. But people I know with migraines, they feel it way before the migraine hits and not my case.

Peter Burpee: Going off of Daniel and Channing, I was the same way. I never got any auras. It was the type of thing where I'd have a seizure, I'd be one place before it and then wake up in the back of an ambulance or in the hospital or in a completely different place and just had no idea what happened. So can't really speak much to the auras.

Channing Seideman: I am fortunate enough to have a seizure alert dog. Yeah, I have my Bishop and he is incredible. He learns that smell and he does help me out with that warning.

Daniel Allbeck: Can he tell that you're going to have a seizure before you do or does he just help you after you've had it?

Channing Seideman: He's my second service dog. So my first one, she helped me more with the response part, the afterwards part, with the getting the meds, the getting help part. Bishop, he can help me with before part, with the warning, he goes and gets my mom and he'll bring my mom to me up like five minutes ahead of time.

Daniel Allbeck: So he can sense it before you can sense it?

Channing Seideman: He can, absolutely, yeah.

Daniel Allbeck: That's really interesting.

Channing Seideman: Yeah.

Brandon Laughlin: And I'm so glad you got to address that because I was actually jump into that question as well, Channing because that was great. Because I know a lot of people have questions about seizure dogs and whether they can help their specific type of epilepsy because like you all said, your experiences are different. Some people experience the auras. And it does really depend on what type of epilepsy you have. Because there are so many different types of epilepsy. Can you talk a little bit more Channing about the things... You went into detail, but is there anything else that Bishop helps out with on an everyday basis for those people who might be considering getting a seizure alert dog?

Channing Seideman: Yeah, it's really funny, Bishop, the organization I got him from, Canine Assistants, they're incredible. They're a bond based, so Bishop doesn't really know sit or stay or down, that's... He's really stupid for really smart dog. But once you have that bond, they just know and it's literally all about the bond. He knows my off days before I do. He knows if it's going to be a good day that I can go to the barn or if it's going to be a bad day and I need to stay home. He'll usually, if it's early in the morning, my mom might come and she'll bring my mom to come up and check on me. Mornings, I struggle with my increased seizure activity more than day or...

Daniel Allbeck: Me too.

Channing Seideman: He definitely, he knows and he goes and tells my mom for sure.

Brandon Laughlin: Great. Okay, so we're going to keep with these questions on seizure control and daily medications, things like that. So somebody wrote in, what was... They have a child who's moving and transitioning from pediatric care to adult care, which I know can be a struggle at times, especially when you've had your same pediatrician for your entire life and they know you so well and then you have to move and go into adult care. Can you guys provide some advice for parents and or children who are going through that journey and how you make sure that you find the right doctor and how you take control of your own health journey, which I know can probably be a struggle for you and for your parents?

Channing Seideman: I didn't have a pediatric epileptologist. At the time that I was finding an epileptologist, there weren't that many comprehensive epilepsy centers around. So we went through quite a few before we ended up at the NYU Comprehensive Epilepsy Center with Dr. Blanca Vazquez. And what we learned through that process was you really have to find the epileptologist that you feel comfortable with because you're the one who has to speak about your diagnosis, which is hard enough, and to ask the question, even harder, you want to be comfortable with that doctor. We saw doctors who maybe didn't answer the question, who maybe my epilepsy was changing and we needed a more specialized doctor, but you really are your own advocate and you really do need to find that doctor that works for you because that's your main communication. You [inaudible 00:11:47] with your doctor.

Daniel Allbeck: That's one of the things I've learned the most is about finding your doctor because I've had doctors that just threw more medication at the problem. As a person with epilepsy, I think my goal, I don't know the rest of you, is to get off as much medicine as possible. At the moment, that's not working for me, but. Yeah, find a doctor, find a specialist. Don't just do a neurologist, find an epileptologist, find a center of excellency like you found one in NYU, is that what you said?

Channing Seideman: Yeah.

Daniel Allbeck: Mine is in UC Irvine, but my doctor trained at the Cleveland Clinic, which is my understanding the best there is in the country, which is pretty close to where you are, I think, Channing.

Channing Seideman: Yeah, now that we've moved to a city and we have that availability to see a specialist closer to us. We're now in the care of Dr. Michael Privitera, but initially we were in a small mountain town and had to make the drive to Denver for that specialist.

Daniel Allbeck: Yeah.

Peter Burpee: Yeah, I think in contrast to what Daniel and Channing said, I was very fortunate to get linked up with Dr. Colin Roberts up at OHSU since I was very young a child and his plan, his methodology worked great with me and my family and didn't rush anything, wanted to make sure we were all on the same page about everything, didn't want to over-medicate. It was very conservative with his approach. And that worked all the way time until I started going to college and graduated to college and after graduating from college moved to New York. So I got hooked up with the whole NYU [inaudible 00:13:29] system, like Channing said. Had been fortunate enough to be working with some great docs there.

And another thing I'd like to add is that I think the network between doctors in the epilepsy sector is very tight, actually still in contact with my childhood neurologist, Dr. Robertson. He knew of those doctors in NYU, so he was able to point me in different directions and like I said, have been very fortunate enough to not have to seek around for many different doctors.

Brandon Laughlin: That's fantastic. And you are right, there is that network and taking advantage of that is so important as well. So I'm actually going to stick with you, Peter, because you brought up a point that, actually a question that just came in addresses, and that is what advice do you have for not only those that may have a child that is going into middle school, high school, or even at the college level, how to balance epilepsy and the demands and the stress of the academic world? And maybe share maybe some of your experiences or maybe some of your advice or maybe some of your thoughts. And so since you addressed it first, I know you probably all have something to say about this, I'm going to start with you, Peter, on that one.

Peter Burpee: Yeah, absolutely. My epilepsy journey really got going in high school and I certainly remember it, but was very fortunate to be surrounded by a very supportive group of teachers and classmates and obviously very much cared about my academics, but it did take some extra time outside of the classroom. It was going in before class started and spending time in the mornings and spending time at nights one-on-one with professors. So while epilepsy did hinder my learning a little bit during the day-today, I think that I was on the same page with my professors to put in that extra work to get back to where I wanted to be and even get back to ahead of that.

And then as I moved along to college, as far as the balancing act goes, sleep was always number one for me. I was always trying to get at least eight hours and I'm sure Channing and Daniel will also speak more to this, but have always been trying to get my eight hours. And it depends on what your priorities are, but I really, really prioritized my academics, really prioritized sleep and wanted to make sure that those stayed balanced. In college and high school you're going to run with those late nights and even in work too, but it's all a balancing act and sometimes it's not always going to be balanced. But I think just living a healthy, a fit lifestyle to get that same balance as much as possible, it's been perfect for me.

Brandon Laughlin: And then Daniel, did you want to add anything to that?

Channing Seideman: Middle school and high school were also tough for me, I found that I fall into a cycle of I would have a seizure in school, get behind the work, get stressed because I was getting behind the work and then that stress would cause a seizure. That's the cycle I fell into, but I found a tutor was very helpful for me personally and he really... I relied on him heavily throughout med school and high school.

Brandon Laughlin: Great.

Okay, I'm going to stick with this theme, but we're going to switch to a slightly different theme and we're going to talk a little bit more about the stigma because this is a question that comes up a lot with people that call into CURE Epilepsy or that we run into in many of our community events. So a lot of people try to address how can we alleviate some of the stigma that's involved with epilepsy. I am going to ask each of one of you any advice you have or when and why did you choose to share with others that you have epilepsy and maybe a little bit about how you did that, how you shared that.

Daniel Allbeck: I'll jump in. I'm a recent teacher. I just started teaching the last two years and I have to share it with my students. The reason is because if I have a seizure in class, which has happened, I don't want them to be scared, I want them to know what to do. So usually when I'm sharing about my epilepsy it's so that people just understand and if you want to dispel stigmas and myths, then tell them and then let them see that you can still operate a normal life. If for example, the stigma is, "Oh, people with epilepsy, they can't do anything because they're just so sick." That's not true. But people won't know that if you don't share with them that you have epilepsy and then they can witness, "Oh, he's capable of holding down a job but still have an epilepsy." So mostly when I share, I answer any question anybody has and it's so that, one, they know what could happen, and then two, what to do if it did happen.

Channing Seideman: I found that knowledge is power with epilepsy and the more you know, the more you can help try and take that fear out of it, just getting more comfortable around it. I think that putting it in context can also help a lot with it. For instance, I get asked a lot riding horses, that's in epilepsy, that's just not going to mix. For me though, when you put it as I feel more safe on a horse than I do crossing a street because I could just space out crossing a street, that gives them some context and I think that can help a lot.

Peter Burpee: Yeah, I think piggybacking right off of both, I always wanted to feel like I was living a normal lifestyle. So I've never really felt any sort of stigma. I've always been open and honest with my friends, teammates, professors, anyone around me that I have it. I don't think anyone really around me has thought twice or blink twice about any of it. So I think that the whole knowledge power thing is spot on.

Daniel Allbeck: Yeah.

Channing Seideman: I wasn't ready to share it myself. We developed seizure cards for that just to make sure that people that were with me every day, coaches, teachers, they could have the information, what to do, what not to do, and I didn't have to share it because I wasn't comfortable, hadn't accepted it at that time.

Daniel Allbeck: When I first got it, I didn't want to share about it either. In fact, I tried to act like it didn't happen, just go on and live my life and pretend like I didn't have epilepsy because it upset me so much. But as you guys probably know, that's not the way to go. You should advocate for yourself and seek as much help as you can.

Brandon Laughlin: All three of you gave great advice and I love the knowledge is power theme because that is very true. And so Daniel, I was leaning towards actually maybe ending with this question, one of the ones that was prepared for us in advance, but you brought it up and this is a great question to follow that last one, but if each of you could dispel one epilepsy myth, what would it be and why?

Channing Seideman: For me, it would be that there's two, it would be that there's multiple types of epilepsy. So you don't just think of the generalized tonic-clonic that scares everybody. And then the second one is that it's contagious. I think that just brings extra fear. It can have a huge social impact on your social life.

Daniel Allbeck: I'm always surprised when I hear that one, that people might think it's contagious. So yeah, if you get that, dispel that right away.

Channing Seideman: Yeah.

Peter Burpee: I think the one that I'd like to dispel that makes me laugh a little bit is that there's only one type of seizure and it's caused by bright flashing lights and loud noises.

Daniel Allbeck: Yes, that's what... You took my-

Peter Burpee: I got that one in college a lot and that wasn't the case for me ever. I always got some laughs out of that one.

Daniel Allbeck: And I am photo sensitive, but I can also go to a concert with strobe lights and have no problem, but then I could just turn my kitchen light on and it can start triggering one. It's not consistent, nothing about it is consistent. I said the one thing that is consistent, I think Peter hit it, is sleep. If I don't have good sleep, I have episodes.

Brandon Laughlin: Very true. We hear that a lot. But go ahead, Channing.

Channing Seideman: Yeah, I agree with Daniel. Stress and sleep, it's-

Daniel Allbeck: Stress too. Yeah, stress is the other one.

Brandon Laughlin: So this is actually a question that came in the chat a little earlier and so it may not apply, but I'm going to go ahead and ask, do any of you have explored any sort of natural prevention or natural remedies for the treatment of your epilepsy?

Channing Seideman: I have. I've tried acupuncture for sure and biofeedback as well. Anything to help with stress and it never hurts to try something.

Brandon Laughlin: Just real quick, the acupuncture, did that help with any of the epilepsy or its comorbidities?

Channing Seideman: It didn't in the end, but not to say that it didn't do something.

Daniel Allbeck: Peter, have you ever tried anything holistic or something like that?

Peter Burpee: Never anything like acupuncture, but I think that my indirect way is always getting a lot of exercise. It's a way for me to blow off steam and just de-stress, especially after long weeks of work or just long weeks in general.

Daniel Allbeck: The only thing I've ever tried besides the normal anticonvulsant medicine is I tried CBD oil. I read that this was mostly for childhood epilepsy, that they had done some studies that said CBD can reduce either the number of seizures or stress or something, but there's no research, I was guessing how much to take and in the end it didn't appear to be making any difference and it was really expensive, not covered by [inaudible 00:24:50]. I deemed it ineffective, but it's mostly because of lack of research. I have no idea how much I was supposed to be taking.

Brandon Laughlin: Very true. That is a hot topic in the epilepsy research world right now. So yes, I feel as though we're going to see a lot more research and scientific papers and everything coming out about that in the very near future.

Okay, we're going to talk a little bit, and I think Daniel, I'll probably start with you on this one because I know that a few of you have experience in this and Channing maybe you can jump in a little bit about this, but we get a lot of questions here about surgery and devices as other ways and other treatments to epilepsy besides just your standard anti-seizure medications. So can you tell us a little bit, I know you mentioned earlier about your surgery back in 2021, so tell us a little bit more about that, what type of surgery you had and the results that you've experienced.

Daniel Allbeck: Okay. I just call it brain surgery. I use casual terms, but it was a craniotomy with the resection, meaning, so most of my seizures are in my left side and unless it was a generalized clonic but I'm not getting those because of the surgery. But they did a resection, so they took a chunk out of my brain. I have pictures. I'm not going to show you guys. It's really weird to look inside your brain and see a hole. I think like anybody, I was frightened, I did not want to do it. I'd been putting out for a long, long time.

But that's how I got connected with CURE Epilepsy. My parents actually went to a science convention that you guys were hosting. I'm not really sure because I had never heard of CURE Epilepsy, but they were just diving into research that I just wasn't willing to do because I was just too stubborn. I didn't want to admit that I should be doing something about it. I was like, "It is what it is. The doctors will fix it or they won't and shouldn't." That's a terrible attitude to have, just for people out there.

So the doctors finally talked to me and said... I had several MRIs, I had overnight EEGs and stuff like that. And I also had them induce seizures purposely so they could see where the electrical activity was happening. And it turned out that the grand mal seizures were mostly coming from here, so that's where they did the surgery. But I was having in my occipital lobe, I also had vision issues and that that was not treatable through surgery. So I have to stay on the medicine for that.

But I guess if I was going to talk to somebody about surgery, it's getting over the fear and then talking to your epileptologist and the surgeon, because they're going to work hand in hand, ask them what they're exactly going to do, what kind of progress do they think it'll make? At first, I was under the assumption that I would be seizure-free afterwards, but after talking with my surgeon, he said, "No, that's not possible" because of all the places that I'm having focal seizures from. But that it probably would stop the generalized seizures, which it seems to have. And then hopefully over time I'll be able to get off most of my medicine, but probably not all of it.

So research and try to get past the fear because it was very scary. But it's not so bad once you get it and you're done, like you're asleep, you wake up and it's done. It actually wasn't that bad, the process, the surgery itself, but leading up to it was frightening.

Brandon Laughlin: Absolutely understandable. Channing, I know you've had some experience with devices. Why don't you tell the audience a little bit about yours?

Channing Seideman: Yeah, so I have the VNS device, the vagus nerve stimulator, and we went with the VNS, it was a last resort. Surgery's always the last resort, but for us. But one reason we went with it was I'm on four medications right now and the amount of medications to control the seizures took an impact on my quality of life more than the seizures themselves it did to control them because of the side effects. So one of the hopes with the VNS was that we would be able to lower the medication I was on to help reduce some of the side effects, improve quality of life.

Daniel Allbeck: Were you able to lower your dosages?

Channing Seideman: I am, yeah. On one medication I have lowered that dosage by half actually. And we don't know how the VNS works. We don't know what it does. I have heard stories of people with Parkinson's who have stopped the VNS and they've noticed an increase in their shaking and tremors. So it is doing something just not sure what. The surgery itself was simple, as was recovery. Recovery was not bad. The thing that I struggle with the VNS is the loss of breath. There's a setting on it that when you have an increased heart rate, that is an indicator for before a seizure. So it will go off automatically. But if you're working out and you get an increased heart rate that can... You lose your breath. At least I do. And so that's one of the things that I struggle with the VNS living with it day-to-day.

Brandon Laughlin: Thank you. Thank you both for sharing that. I think that's helpful information, especially for those people that are looking at those last resorts.

Daniel Allbeck: Can I add something?

Brandon Laughlin: Yeah, go ahead, Daniel.

Daniel Allbeck: When Channing said that she takes four meds, so do I, and ideally the point of the surgery was that we could at least reduce it to three. I used to only take two. Like I said, some doctors tried to throw medicine at it and as you guys probably know, you can't just stop taking a seizure medication, you have to wean yourself off of it. VNS, they looked at it for me too, wasn't going to work they said, but the hope that you'd be completely off medicine, it's different for everybody. I was so hopeful and I wasn't able to get off any of them, slowly working down one of them, but I'm still on it. So I guess what I would say to some people out there who are considering it is you might have to be prepared that you'll still take medication for life even if the surgery does improve, which it has for me. And it sounds like it has helped Channing too. It didn't fix everything.

Brandon Laughlin: Right, and thank you for sharing that. So got a couple more questions. Just a reminder for our audience if you do have any other questions, go ahead and submit those into the chat and I'll get to those. But one question that we get a lot here and actually a statement that I hear a lot as we go out to different communities is about not necessarily the seizures themselves, but that many parents and many individuals with epilepsy actually struggle more so with some of the comorbidities or the side effects that go along with epilepsy. Can each of you maybe describe maybe some of those comorbidities that you've experienced and any tips or tricks that you've had in alleviating those?

Channing Seideman: Nausea, dizziness, just general malaise, I spend a lot of time in bed resting. I probably only have a good few hours in a day that I have that energy, if I have that, those few hours on a good day. But yeah, the amount of time I spend in bed resting and sleeping just to catch up is a lot for me.

Brandon Laughlin: Peter or Daniel, did you have any comorbidities experienced?

Peter Burpee: Yeah, happy to go. Fortunately I've been seizure-free for I think six or seven years now. So just pulling some of this off the top of my head. I remember after having a string of pretty bad grand mal seizures, same thing Channing said, your body's exhausted and just spending so much time in bed and I don't think you really realize how long it takes for your body to recuperate after having a couple of them until you actually go through it. So that was the big one. And then the second other one is definitely memory loss for me. A good chunk of my probably sophomore year, maybe even junior year of high school are pretty forgotten about, pretty cloudy just from going through multiple grand mal seizures a week. It's definitely a bummer to not be able to remember a large part of that part of my life, but if that's the worst of it, then I'm more than happy to live with that.

Daniel Allbeck: Yeah, piggybacking, it's how exhausted it makes your body after you have a grand mal or even when I have my more minor absence seizures, I don't think people really get it. I'll sometimes have to be in bed all day if I have eight hours, it's crazy. And then sleep a normal night. It's ridiculous. Sometimes people think I'm making it up, so maybe that's a stigma, is we really are freaking exhausted and it's not possible to do something on a day where I just had a grand mal. And even when I have my confusion episodes, so that's something I still get. I'll get memory loss, like Peter said, but it's just for the period of time where it happened and I won't even know that I had this little event for 10, 15 minutes and then I'll look at my family and I'll say, "What? Did something weird just happen?" And they'll be like, "Yeah, you had another episode." That is exhausting too. It's tough.

I'd say the exhaustion is definitely the number one comorbidity and then forgetting periods of time. When you have a grand mal, luckily I haven't had one in two or three years, but I don't remember anything. Like Peter said, absolutely nothing. But unlike Peter, it's not for an entire year, it's only during the time when I'm having it plus or minus maybe five or 10 minutes

Channing Seideman: Off the memory thing, that was an issue for this... Not a comorbidity, but for school. I had plenty of absences that I wasn't aware of during the school, missing tons of information and that was... Which teachers think you can be daydreaming, maybe the other students were, just an everyday space out, but you can miss just the question on a test or lots of missing information for school with that.

Brandon Laughlin: Channing, we actually had somebody in the chat, they wanted to know, if you don't mind sharing, what kind of seizures did you say you had?

Channing Seideman: So my seizures have changed over the years, but I've had tonic-clonics, absence and myoclonic jerks. I've also had seizures that just affect certain parts of my brain where maybe I'll lose my vision or maybe I can't talk, maybe I can't move. So they've changed over the years, they've gone, but they're very dynamic with me.

Brandon Laughlin: And thank you for sharing that.

And so we have another question from the chat as well. We have a woman whose son is 11 and he gets very stressed sleeping by himself, which is obviously a valid concern. And even though their doctor says to let him sleep alone, she feels horrible leaving him. Do any of you have any experience with that or any tips that may have worked for you in the past as far as sleeping alone versus some sort of maybe monitor system or anything like that?

Channing Seideman: I sleep with a watch and it has the abnormal motion detection on it. There's two watches or technology that I'm aware of for that abnormal motion. One is Inspyre and then the other one is called Embrace, and those are two apps I believe that you can do with the watch for abnormal motion detection.

Brandon Laughlin: Thank you. Did either of you have-

Daniel Allbeck: Peter, you said you had seizures when you were younger, right?

Peter Burpee: Mm-hmm.

Daniel Allbeck: Because I can't really speak about sleeping alone because I was 22 when I first had mine, so I was comfortable sleeping alone. But an 11-year-old, I could understand that being very frightening, especially if he has grand mals or tonic-clonics I'm not sure. But for me, I don't mind sleeping alone if I had a grand mal, like Peter said earlier, I usually just woke up in an ambulance and so it went from asleep to ambulance. There was nothing scary in between, but I never did it as a child, so I was wondering what Peter went through.

Peter Burpee: Yeah, can't really relate a whole lot to the whole sleeping thing. I don't think I had many, if any, seizures while I was asleep. Fortunately I had a twin brother and we shared a room, so I always had a built-in person that was always there for me, but can't really relate.

Brandon Laughlin: Interesting. Yeah, no, and it's an important topic too because it's a topic of conversation that I think many, many individuals and even many healthcare professionals are afraid to address is the consequences of sleeping alone and the consequences of SUDEP. So that is definitely a conversation to have with your doctor and your entire medical care team as well.

I'm just checking to make sure there weren't any other questions because I do have one final question to kind of end with you, with everyone, because over the time that we've gotten to know each other and there's been kind of one common theme of uniting the three of you and even on our conversations leading up to this event, it was really exercise, athletics or even organized sports that all three of you have that in common. I know that people have talked about this, people ask me questions all the time, is it safe for my son to participate in this and is it okay even if there's risk of contact? Things of that nature. So can each of you tell us a little bit about how you've used exercise, sports, any of that as an outlet to combat the everyday struggles of living with epilepsy?

Channing Seideman: Daniel?

Daniel Allbeck: Mine's actually the opposite. I can't play as many sports as I would like to. I was an athlete in high school, a three sport athlete, and then I started having my episodes. And then medication on and off helped, but I wasn't able to play. I pole vaulted. There's absolutely no way I would be doing that right now. But I played baseball too. I love baseball. As I got older, transitioned to softball and I've found that I was having episodes when I was doing things that were athletic, but I think I just am not as in shape the way Peter said it. If I was more on top of being healthy, I think that I wouldn't be having these problems. But I'm also pretty photo sensitive, so if I'm playing softball at night under the lights, that's when I had the biggest problems, it was really... So what I wanted to know because I know Channing was the one that brought this up first is what do the two of you do to be able to play your sport and not have any issues?

Peter Burpee: Go for it.

Channing Seideman: My [inaudible 00:41:35] sports were skiing and horseback riding. There were two issues with skiing. The one was the obvious, the chairlift. Having a seizure on the chairlift is not a smart idea. We devised a seatbelt if you will. It's a climbing harness, but we cut the legs off the climbing harness and we threaded what was remaining of it, which was simply just the belt through the belt loops and we attached a carabiner little daisy chain, and that daisy chain acted as a seatbelt that I would throw over the back of the chairlift and connect in the front of my ski pants. The second issue with skiing was they didn't want me going a hundred miles downhill racing. That was the one minor detail they said. Which was okay, because I like the bumps personally, so that was all right.

Horseback riding. I wear a vest that connects to my saddle and if I come off the saddle it will blow up like an airbag and 0.09 seconds before I hit the ground and it protects my neck, my internal organs, my spine, my back. But like I said, for me, crossing the street is more scary than riding a horse. It's just all about how that contacts. I've had seizures on horses, I've had seizures on the mountain. It's like any sport, you're going to fall off, you're going to get hurt, but maybe you just had a seizure as the cause of it instead of a big spook from a horse or you wouldn't really high off and jump. Maybe you just had a seizure and you've got an extra toboggan ride down, which is not always fun, but whatever, it can be worth it.

Daniel Allbeck: I've had that toboggan ride down, but not from a seizure, just from an accident.

Channing Seideman: There you go.

Brandon Laughlin: Peter, I know you're running a marathon for CURE Epilepsy here in the fall, which is exciting. Anything to add to that?

Peter Burpee: Yeah, just to directly answer Daniel's question, I was having seizures so frequently and I within such a tight band of time that I just put a pause on all sports I was playing, which was very frustrating, I'm sure as you can imagine for a 16, 17 year old kid where sports is their entire life. So we just followed the doctor's orders and put a pause on everything until we got the clearance from him and was fortunate to be able to get back on the lacrosse field, get back skiing, but get back playing basketball, get out surfing. Definitely all probably not the safest sports as far as being in the ocean on top of an icy mountain out playing a contact sport. But I think it was ultimately the doctor's call and what my family felt comfortable with, what he felt comfortable with and yeah, again, was fortunate to get back out there.

Daniel Allbeck: So the obvious concern when we were playing sports is are you going to injure yourself? Are you going to have a seizure and are you going to be injured? I've been injured in so many different ways that I stopped caring about that and I was more interested in can I even perform in this sport? It's not really about am I going to be good at it or am I going to hurt myself? I just want to be able to play a sport. I love baseball and I just want to do it and it's still a struggle. I think that as you identify your biggest triggers, you have to decide, "Oh, that's not a sport for me." Like bright stadium lights, I love baseball but I can't do it.

But I can still snowboard. I like to do it and I don't have grand mals anymore since I had my surgery, so it's fairly safe. I might have an absent seizure, in which case it's not the safest thing, I should probably get a vest or something. But the one that stands out to me, the scariest moment, I had a grand mal in the ocean and my girlfriend at the time dragged me out of the water and I woke up to an ambulance and that's when I realized "I can't be doing this anymore." And that was only about three years... No, it was like four years ago. That was such a hard moment because I love the ocean. And it also just put an exclamation point on all sports like I was talking to myself, "You need to be more careful and just stop thinking that you can do anything. Unfortunately is not the case."

But what was cool, I had my surgery and two years ago I was able to go back in the water confidently in the ocean with people there. But that was a great moment for me. I don't know. I want to bring up another subject, but I'll let us move on to the next question first.

Brandon Laughlin: Actually, that was where I was wrapping up, but this is a conversation so please do bring up that topic.

Daniel Allbeck: I want to bring up depression. When I first got diagnosed, like I said, I basically tried to ignore it, it hit me hard and I was like, "No, why?" You ask yourself why? And I was like, "Nah, the doctors will fix it. I'll be fine." And then when you realize you're not going to be fine, I started spiraling into depression, isolate myself, which is not helpful for depression. There's a stigma about mental health and I think that when it comes to severe chronic illnesses like epilepsy, that people won't talk to us about that side effect. They'll be happy to talk to us about our diagnosis, but nobody really wants to consider how important your mental health is as well.

The depression was real, it took a lot of work to get out of it. And having a solid support system is the easiest way to get out of it and the best way to live your life. Without my family, I have no idea. Definitely absolutely no sports. They drive me everywhere because I can't drive. I know that there are people out there that are going to be depressed, but they don't want to talk about it. Talk to anybody that is close to you, it's important.

Channing Seideman: I think sports can also extremely be helpful with socializing. I know that can be difficult and finding common ground or that common interest in sports, you can find a family within your dedicated sport that you love and that can help as well.

Daniel Allbeck: This is a kind of sad, but I was playing softball team and I was having confusion episodes under the lights and I got kicked off the team because there were enough times where the balls hits to me and I just did something weird. This is what always happens, you wander away or something and they didn't want to have me anymore. That was depressing and it's been hard to find... Basically, those people are not my friends anymore, but had to find a new group, start playing softball with people that understood it a little better and are kinder, more understanding people. It's really important.

Brandon Laughlin: I'm so glad you brought that up because I was actually surprised that in our early conversation about comorbidities that depression never came up because obviously that is the number one concern for not only those diagnosed with epilepsy, but also their family members and their loved ones.

Daniel Allbeck: My parents and my sister, they could see my depression and I could see it rubbing off on them. They started getting depressed. Then it was a cycle

Brandon Laughlin: Actually, because I told everyone this is audience driven, we did have another question come in, so I'm going to go ahead and address that one. How do you all express concerns about medical advice, whether it be medications or surgical interactions, to your care team without creating any sort of negative dynamic? Do you have any advice for them?

Channing Seideman: For me, I don't think that's ever been an issue. I think always... Knowledge is power, again. If you have a question and even though there's that awkwardness, this is your health, this is-

Daniel Allbeck: You got to ask it.

Channing Seideman: Yeah.

Brandon Laughlin: Good advice. Good advice.

Daniel Allbeck: I would also add to that, seek a second opinion. If you don't think your doctor's listening to you or if you don't agree with the methods, seek a second opinion. That's what ended up leading to my surgery. I got a new epileptologist, new doses of medicine and things started improving slowly. And they're still not perfect, but they are still improving. So just one day only being on one or two meds.

Brandon Laughlin: Absolutely.

Channing Seideman: It's like an opinion, I agree with Daniel on that. That's huge.

Brandon Laughlin: I agree. And so yeah, I think that is a great way to wrap things up. I will go ahead and give it up... If there's any advice or tips or anything else that I didn't cover in the questions that I asked or that came up from our audience, do any of you have any wrap up statements or anything? I know we heard some incredibly powerful and great information such as knowledge is power and seek second opinions. Is there any other advice you'd give anyone out there, whether they be an individual with epilepsy or a loved one?

Daniel Allbeck: Don't give up.

Channing Seideman: Trial and error. You'll find it eventually, a lot of trial and error.

Daniel Allbeck: Yeah, it's a battle, lasts a while, but you just got to keep fighting, don't give up.

I work at a school, my principal always gives this daily message my students to the whole school and it's "You have no idea what other people's personal lives, we're all going through something that you have no idea about. So be kind to each other." I don't know, you have no idea what other people are going through and they don't have any idea what you are going through either. So you can either share that with them and help them understand or you can bottle it in and it's going to be easier if you share with people so that they can, not commiserate, but just understand.

Brandon Laughlin: Daniel, that's advice for anybody, whether they have epilepsy or not. I think that's [inaudible 00:52:49] advice.

Daniel Allbeck: That's a life advice, right?

Brandon Laughlin: That's life advice right there. Absolutely. Absolutely.

Peter Burpee: Yeah. Definitely agree with what Daniel said. Don't give up. I remember how frustrated I kept getting once seizure after seizure after seizure and there is a light at the end of the tunnel, whether it's one form of medication, surgery, whatever. There's a light at the end of the tunnel. Just keep fighting.

Brandon Laughlin: That's a great way to go ahead and end this in. And that's inspiration from you Peter as well. You've been seizure free now, you said six or seven years now, right? But yet you're still bringing awareness and fundraising and running a marathon in New York this fall. So kudos to that.

Daniel Allbeck: Yeah, absolutely.

Brandon Laughlin: Kudos to all three of you. You all are an inspiration. You're an inspiration to the epilepsy community. You're an inspiration to me, as somebody that doesn't live with epilepsy. I appreciate all of you and everything that you do for not only our organization but the epilepsy community as a whole. And thank you for joining us today and sharing your stories and opening up with everyone here. And thank you to our audience for asking some great questions, those that asked in advance and those that were on the presentation today.

Today's panel will be made available so there will be a recording of it. This will be made available on the CURE Epilepsy website tomorrow. Also, tomorrow make sure you do join us on our third and final day of Unite to CURE Epilepsy as we unite to give. And you'll actually hear from a CURE Epilepsy champion, another CURE Epilepsy champion who actually does a huge run walk for us. Also, I know there were lots of questions about medications and technology and devices and surgery. There is more information that can be found on the CURE Epilepsy website on our Understanding Epilepsy section. So I encourage everybody to visit that as well.

Thank you all again. I want everybody to... Wish you all a great evening and be well.