

Maureen Podcast Edited

>> MIZUTANI: Welcome and thank you for joining "Disability, Inc." I'm Jean Mizutani from INCLUDEnyc, here with Maureen Surin, an Illinois parent who refused to give up when western medicine was not helping her daughter, Ashley, now a beautiful 14-year-old. Two years ago in 2018, the Surin family made history when Maureen's advocacy led to Ashley's Law, which authorized the use of medical marijuana in school for the first time. Welcome, Maureen.

>> SURIN: Thank you for having me.

>> MIZUTANI: It's my pleasure. When I first heard your story, it was so exciting, I knew we had to share it. Let's start with Ashley.

>> SURIN: Well, Ashley is now 14; but at the age of 2, we experienced a major bump in life. She was diagnosed with ALL leukemia, cancer of the blood, and we underwent quite a bit of chemotherapy for two and a half, three years. Nine months into the chemotherapy, Ashley developed seizures from a high dose of one of the medicines -- we believe methotrexate. We began many neuro meds on her, all the way up through puberty, from age 3 through age 12.

She went through so many EEGs. She had daily seizures. We were on so many pharmaceuticals, we lost count. As puberty arrives, everyone knows with seizures, they can get very difficult to manage. That was exactly our experience with our daughter.

It happened to be a gorgeous summer afternoon. Daddy/daughter said, "Mom, you need a break. We're going to go off on our own and give you your own spa day, your own personal time." So daddy/daughter went off for the day, visited an auntie and uncle. On the way home, they stopped at a grocery store to stock us up. God bless Ashley, she fell backwards in a grocery store, and cracked her head on, like, a marble -- (begins to choke up) pardon me. Sorry, it chokes me up every time I tell it.

She had had a seizure and fell in the grocery store. It was close to her medicine time, so we weren't sure if it was another breakthrough, or just time for the medicine. We went to the hospital, and after several days of scans, they wanted to do brain surgery, because she had had a concussion and had some bleeding in there. They didn't feel it was going to cause any further brain damage, but they said, "We gotta get in there, clean it up."

So that concussion that Ashley had at age 12, after seven and a half, eight and a half years of neuro medicines, told my husband and I, "That's enough. We need to take a new path. This little girl needs to be around. And if she's going to be around, we need to do something different."

It was an eye-opening time for us, and we started reaching out to naturopaths. One of my best friends from high school told me about an awesome doctor that helped her son get on a better diet and get off some pharmaceuticals. She's right, he was amazing. He referred me to another naturopath, who in the end, these two naturopaths teamed up and were basically telling us our daughter had so much wear and tear on her body from the chemotherapies, from the neuro medicines. Her body is trying to grow. Let's give her a natural diet, maybe ketogenic, lower carbs -- and consume cannabis.

I just cleaned my ear out and said, "Wait, can you repeat that? I'm just kind of having to digest all this." So we did. We started a cannabis regime with this doctor, basically hemp, and the lower carb diet. We took her out of school for a month. And her seizures were diminishing, I will say.

It was exciting to see her giving us longer sentences, and kind of her thought processing was getting better. Her coordination was getting better. Her eye contact was getting better. We were just astonished. So we still experienced some seizures, and we said to the doctor, "Now what?" And she said, "Well, maybe hemp isn't enough. We might need full plant." And we said, "in English?" and the doctor said, "THC."

[LAUGHTER]

So we needed more THC than allowed in hemp. Hemp is 0.3 or below in all 50 states, legal.

When we decided that she did need to move from hemp to the full plant with the THC, and we did apply for the license in, I believe, late September of 2017. We were excited. We thought, okay, this is going to be a great Thanksgiving. We're going to be starting this -- or Halloween. But the wait went on and on and on. So we were e-mailing, we were calling, e-mailing, calling, e-mailing, calling, and the wait was just unbelievable. We didn't understand if they were bombarded with applications, or was our application being denied? Was it lost?

>> MIZUTANI: Who processes those applications? Is it the Department of Health?

>> SURIN: Yes, the Department of Health has a medical cannabis, I believe, division now that -- not sure how big the department is. But they managed to, I give them credit, to improve it in terms of turn-around now, compared to back when I applied. We got the license the December.

The doctor said, "Well, when you get the license, you go in there. You kind of have to ask them --" The doctors can certify you, but they're not all 100 percent trained on what meds help treat which ailments. So it really is trial and error. She just guided me, saying, "You probably need a high CBD, low THC." And that was my guidance when I walked into a dispensary loaded with hundreds of thousands of choices.

>> MIZUTANI: My gosh.

>> SURIN: She can't smoke it, so I can't go, "Here, Ashley, smoke something and you'll feel better."

[LAUGHTER]

>> MIZUTANI: Can you tell us about the license that you just mentioned? Most people are not familiar with that.

>> SURIN: Of course. The license is actually much easier to obtain now in our state. I don't know about all the states. But when I first found out I had to get two per child -- you still need two doctor certifications. So the doctors fill out paperwork, and they send it directly to the state, if they approve to do it for you. Some doctors have fees for it. They did have fees for it, and of course, insurance doesn't cover any of that, because it's all federally illegal still.

But the doctors submit their paperwork. My husband and I, the caregivers, went to get fingerprinted, and we had to photocopy, I believe, our driver's license. I believe they did a background check on us. Ashley had to qualify with several different conditions, and she qualified for cancer, for epilepsy, for her autism, for concussion.

>> MIZUTANI: Wow, she was the perfect candidate, actually.

>> SURIN: As we started the actual medical cannabis in December of -- let's see, this was 2017, we weren't sure what we were doing there. It was really trial and error. By the time we got the license, I visited the dispensary by myself, and they hand you a menu like you're in a restaurant. Hmm, what are the specials of the day? They basically had to kind of guide me. I said, "What do you give to a child with seizure or disabilities?" My daughter is on the spectrum for autism.

They guided us towards patches. That was amazing. She really did well with these patches on her feet that are slow-release CBD and a low amount of THC. At school, she does a pump of oil on her wrist in the middle of the day for kind of maintenance. And at night, she does a drop of RSO on a piece of chocolate.

Actually, this sounds like it was really easy to figure out, but it wasn't. It took us probably a month of trial and error, up and down. The key was CBD or cannabis is low and slow. Everybody reacts differently. Everybody has different inflammation. Everybody has different issues. I said to the doctor, "Why didn't the hemp work?" She said, "Well, your daughter might have had so much damage from the chemo that it killed her receptors."

So the THC in the medicinal was allowing her receptors to open up to take in the CBD and do its magic. I emphasize "magic."

>> MIZUTANI: It sounds like magic.

>> SURIN: It was, it really was, Jean. So then we said, "Okay, this is great. We're getting her seizure-free, almost. How do we get off these neuro meds?" Our neuro-medical doctor was not on board with all of this. This was all the naturopaths helping us. So the naturopaths said, "Well, let's evaluate these medicines. Which is the hardest to get off of? Let's get off that one first." And the one that had the most side effects on her.

The one that she chose, I was really nervous about. It was Onfi, but we did get her off it. But it did take a while, because she was having withdrawal seizures after we started to wean. My tear ducts started going, like, "Oh, no, this isn't going to work." The doctor said, "No, Maureen, you know what? It's patience and it's more CBD." So that led us to the little pump on the wrist about lunchtime. And by god, she was right.

Low and slow, keep a journal, and it really did work. We got over that hump of her withdrawal seizures. Knock on wood, she hasn't had a seizure in two and a half years.

>> MIZUTANI: That is amazing. It's absolutely amazing. I think you probably realize that she had to be on -- she had to follow the plan 24 hours a day. That would have meant taking it when she was in school.

>> SURIN: Correct.

>> MIZUTANI: What happened at that point?

>> SURIN: (Chuckling) Good question. While we were looking at the map and thought, "Oh my goodness, it's not legal in school." That's what the doctors told us. We thought, do we need to go to Colorado?

[LAUGHTER]

They allow it in school, and there's only about five states right now that allow it in school.

>> MIZUTANI: Which states are they? Do you know offhand?

>> SURIN: I believe it's New Jersey, Colorado. Michigan is working on one, and I believe California as well.

>> MIZUTANI: I don't know where New York is in the process. I'm very curious to find that out.

>> SURIN: I haven't heard New York. So we were nervous. We said to the doctor, "How can a medicine not be allowed in school?" She said it's federally illegal. I said, "But it's a state medicine that is a public program. My daughter is in public school. What am I missing here?" She said, "I'll write you a note, but I don't know if it's going to go anywhere."

She wrote us a note to allow it in school. I turned it in to the superintendent, who turned it in to the district doctor. He called me and said, "I'm sorry, I can't help you. It's not allowed in school by state law." We said, "Okay, well, then we'll look into this with an attorney and see what our rights are."

>> MIZUTANI: Wow, so I really admire your advocacy.

>> SURIN: With tears in my eyes.

>> MIZUTANI: It's always like that. I'm not surprised to hear that. That's always the case, and that's also why parents like you get it done, because they care that much.

>> SURIN: I will say, the district's been completely dreamy, Jean.

[LAUGHTER]

>> MIZUTANI: Now that it's come to this point. Tell us the steps you took. I'm sure it was not an easy matter.

>> SURIN: No, it wasn't. I called the doctor, and said, "Okay, so the ride begins, buckle up." She said, "I'm in for this with you. She is, this is going to help not just Ashley, but hundreds of thousands of kids." I said, "Let's go."

I started calling attorneys. Couple attorneys said, "Yeah, no, we might be able to call the Board of Ed and get an exception." I said I don't want an exception. I want it to be the norm.

This could be my daughter's medicine for the rest of her life

>> MIZUTANI: It's a beautiful statement, "I want it to be the norm." That's beautiful.

>> SURIN: Aww, we really did. Several attorneys wanted to help but couldn't or didn't have the experience. Then I hit one attorney that said, "I can't help you, but I think my friend can." I called his friend, left him a message. Heard back from the secretary, and basically said they needed thousands of dollars that I didn't have to begin this type of lawsuit. I said, "Well, thank you very much, but that's not going to help me out right now. Thank you for your time."

Two days later, they called back and said -- the attorney had been in court for the last day, and he reevaluated our situation and really wanted to help us. Would do it for just our court fees. We jumped. She sent us to paperwork and said, "This is going to be federal, because we're shooting against obviously a federal law, but we have a state law, and your daughter has a disability, and that's IDEA." So it was a lot of different laws and conflict.

We went to court, and the district attorney for the school came right up to me, and she said, "Maureen, I just want you and Jim and Ashley to know, we're on your side. We want to help figure this out. We're so happy for Ashley. We want to figure this out together. We're not up against you. We're together in this." That just warmed my heart more than anything in the world.

>> MIZUTANI: Yeah, very encouraging.

>> SURIN: So the judge said, which I thought was cool, too, he said, "If we're all here on the same page, why are we here? What's the problem?" The attorney stood up for the school district and said, "We don't know how to proceed. What do we do here?"

>> MIZUTANI: Right, honest answer.

>> SURIN: The judge said, "Well, you got homework. You gotta go home and make a law." That was so awesome. The attorneys got together. We knew the law was needed. We received a couple phone calls from Springfield, from some state representatives, and they wanted us to come down and testify before education committees. We said, "Of course."

So we had our doctors write as much affidavits they could for us, describing Ashley's condition, and describing how the medicine is working for us like no other. We went out there and testified with her, and showed them that it just -- there was nothing like what we were experiencing with the medical cannabis. It was really giving Ashley and normal life.

That was a unique experience, too. Because following politics, I didn't have time for that in my life. I was taking care of my daughter's everyday health, and wanted her to not have these darn seizures.

But Springfield was really cool. We got to tell Ashley's story. Tell them how many different medicines we were on. One gentleman in Springfield even said, "I can't believe you tried everything." I said, "Well, believe it, we have." And I pulled out a stack of side effects that I had Walgreens print out for me of all her medicines. "Want to see me wallpaper your gorgeous antique building here with all these side effects? They're pretty ugly." They were quiet as a mouse.

We basically knew we were on the correct path. We did some more testifying in Springfield with another committee the following week. Basically, they had a lot of questions about the medicines, the CBD, the THC, the smoking and all that for school, and the different rules that might have to come into play for school. Then they said they did need to make the law. So we were kind of collaborating with the school and the state reps and our doctors.

They put together a shell bill in 2018 that was signed by the governor. Basically, it did allow medical cannabis in school that had to be an infused product, obviously not smokable. And that's what Ashley had. She had a patch, and she had an oil for her wrist.

>> MIZUTANI: Were you there to witness the signing? Because I'm sure that was a really exciting moment.

>> SURIN: We were. We did see the Senate final vote, and then a couple months down the road, we did get invited to the governor's office with the rep, and watched him sign a private signing. We got a little copy of the law sitting in our living room, proud for Ashley. It was really cool. The governor said, "Thank you for calling this to our attention."

>> MIZUTANI: Congratulations, because look how much good you've done. Like you said, it's the norm, not the exception, and other children will benefit. So it's a beautiful thing.

>> SURIN: My little girl, she means the world to us. To save her with that was just unbelievable.

>> MIZUTANI: And only you could do it, which makes it even more unbelievable, really. A parent's strength is incredible. We do some amazing things. This is just one example, but it's incredible. How is Ashley doing now?

>> SURIN: She's doing great. She just entered virtual high school, and she's growing. I think she's going to pass me by in height this year. She's been on the same regime for medical cannabis since January of -- let's see, 2018. So we haven't touched her medicine regime. It's just been like a dream.

>> MIZUTANI: Because it's working.

>> SURIN: I can't fix what's not broke.

>> MIZUTANI: That's right. It's working. Now, the law itself, Ashley's Law, how is that working? Are you familiar with what's happening in the state? Tell us about it.

>> SURIN: It's going great. We had a shell bill in 2018. We had to edit it with them in 2019 to allow a little bit more protection for the nurses and the school, and to also allow it on school buses, and after-school activities. So we did work with a different representative, because there were edits needed for the bill.

The representative that carried through the recreational bill helped make edits for Ashley's Law, because it also was somewhat affecting the recreational law, too. So we got to help out with some of the edits. Then witness that signing as well. It's been amazing, truly.

We haven't had, knock on wood, any more bumps with school. School's very grateful that it went through, and they're protected, and they feel safe, and they're glad Ashley is safe. I think we've just amazed some of her teachers and therapists with her progress since we've made this medicine change.

>> MIZUTANI: People talk all the time about making an impact. Just imagine -- just imagine. I mean, this is enormous.

>> SURIN: I would love to write a book someday if I can --

>> MIZUTANI: I think you might. You're an interesting person, too, Maureen. I know that you were in publishing. Tell me about your background and what you're doing now.

>> SURIN: I was. Those are lifetime friends and memories and experiences, too. I went to school in Iowa, Loras College. I graduated from the liberal arts school with English writing and psychology. I went into a brokerage for a year. Don't ask how or why, but I did. Then after a year of brokerage work, I thought, I gotta get into publishing. That's my love.

>> MIZUTANI: What are you going now?

>> SURIN: Now I am working -- my daughter has inspired me so much. I fell in love with a CBD hemp product on one of her doctor's shelves called Receptra Naturals. I love helping other people help themselves. If you don't need a license for the strong stuff, you can use hemp-based CBD, too, to help you. I love Receptra Naturals. Coupon code "Ashley," you can get a little break.

>> MIZUTANI: You went to work for a -- right.

>> SURIN: Colorado hemp-based CBD company. They're in business five years. They have amazing products. I like helping other people. It's just a good feeling. I think their products are

amazing. I can be home with my daughter more, and watch her grow. I've missed so many years, I feel, from all her illnesses and her hospital stays, that it's time for me to enjoy her.

>> MIZUTANI: This is the best part, actually. This is the best time, and I know that you will enjoy. I know that you're not done with your advocacy, though.

>> SURIN: No.

>> MIZUTANI: What are you advocating for these days? I'm quite sure there's something.

>> SURIN: I am helping out -- in Michigan, I'm on a committee with another not-for-profit group called My Compassion with three other women that are passionate about medical cannabis as I am. We're trying to get an Ashley's Law out there. It's actually going to be Caden's Law. The mom Amy in our group is helping. We're helping create a bill that's -- actually, I think the first draft of the language is done. We're just waiting for it to hit the floor, get a vote, and then experience the same thing we are with school. It's just -- Jean, I don't have to pack my house up and move. I can stay in the state.

[LAUGHTER]

>> MIZUTANI: Exactly right.

>> SURIN: Ashley can keep her friends, and we can be near our family and live life like we're supposed to. I would like more states to get on board with this. I would like travel to be allowed. I would like insurance. And Disney, if you're listening, you need to allow medical cannabis in, because they daughter is a Make-A-Wish alum, and we can't go back because it's not allowed. I have a lot of work to do, like you said.

>> MIZUTANI: You do. You've done so much. I'm sure there's a lot of parents that are hanging on your every word, that are listening to this. What advice would you give to other parents?

>> SURIN: I would say don't -- it should go on a T-shirt -- "Don't Give Up." If you feel like you need to try something different, natural diet, natural medicine, darn it, go for it. (Chuckling) Don't let anybody stand in your way and tell you you can't. Because if it's out there, and it's a

state program, and it makes a difference, and there's different qualifications in your state for you to apply and try it, why not?

The side effects from the pharmaceuticals were poisoning my daughter. They were just -- she was just becoming -- her brain was just getting so mushy. I couldn't watch it any longer.

>> MIZUTANI: Don't be afraid to take a leap of faith. We're going to take that to heart. Thank you so much for joining us today, Maureen. Thank you all for joining us at "Disability, Inc." See you next time.