

## About IBD Podcast Episode 119 - The Restroom Access Act

Have you ever been out in public and needed a toilet — but there wasn't one available?

This has happened to everyone who lives with an inflammatory bowel disease (IBD, Crohn's disease or ulcerative colitis), which is why so many of us have "bathroom accident" stories. Needing to use the bathroom is a basic human need, but it's treated like an afterthought. That's where the Restroom Access Act comes into play: a law passed in several states that allows people to request access to a toilet when they live with certain conditions.

There is no such law currently in California. That's hopefully going to change thanks to the efforts of Ashlyn Saltzburg and Kelly Silk. Ashlyn is a teenager living with IBD and Kelly is her mom. Their effort to get a law passed in California is nothing short of heroic. Learn about how they got started on this journey to have the Restroom Access Act passed in California, and how you can help.

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Send your letters of support for AB 1632 to Assemblymember Weber's Legislative Assistant, Raymond G. Contreras: [raymond.contreras@asm.ca.gov](mailto:raymond.contreras@asm.ca.gov)

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Concepts discussed on this episode:

- How the Restroom Access Act Helps Those With IBD: <https://www.verywellhealth.com/the-restroom-access-act-1942432>
- California Assembly Bill 1632: <https://legiscan.com/CA/bill/AB1632/2021>
- Dr. Akilah Weber, Assemblymember, District 79: <https://a79.asmdc.org/2021-2022-legislation>
- Shervin Rabizadeh, MD, MBA: <https://bio.cedars-sinai.org/rabizadehsx/index.html>

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## **[MUSIC: IBD Dance Party]**

### **Amber Tresca (00:03):**

I'm Amber Tresca, and this is About IBD. It's my mission to educate people living with Crohn's disease or ulcerative colitis about their disease and to bring awareness to the patient journey.

### **Amber Tresca (00:14):**

Welcome to episode 119. Restroom access is a huge problem for people who live with IBD. Needing to go to the bathroom is a basic human need, but in many places, it often seems like an afterthought. People with digestive or urinary conditions may decide not to travel or even go shopping because of this issue. Several states have passed a version of The Restroom Access Act. The first was spearheaded by Ally Bain in Illinois. 17 states have a similar law. The gist of these laws is that people who live with a digestive disease should be given access to a toilet at a business, even when there is no public restroom available.

### **Amber Tresca (00:57):**

However, there is no such law currently in California. That's hopefully going to change, thanks to the efforts of my two guests, Ashlyn Saltzburg and Kelly Silk. Ashlyn is a teenager living with Crohn's disease, and Kelly is her mom. Learn about how they got started on this journey to have The Restroom Access Act passed in California, and how you can help.

### **Amber Tresca (01:24):**

Today, we're going to be talking about California Assembly Bill 1632, which is also known as the Restroom Access Act. So, I have two special guests with me here today to talk about this. I have Ashlyn Saltzburg and Kelly Silk. I wonder if the two of you would introduce yourself, because you're mother and daughter, so you probably sound a lot alike. So, Kelly, let's start with you. Would you briefly introduce yourself and let the listeners know who you are?

### **Kelly Silk (01:53):**

Thank you, Amber. Again, my name is Kelly Silk, and I'm Ashlyn's mother. We live in Los Angeles. The Restroom Access Act has been our baby since 2018, so we're very excited to discuss this and happy that you contacted us.

**Amber Tresca (02:17):**

Excellent. Thank you so much for being here and for putting your lovely daughter in front of a microphone to talk to me. Ashlyn, would you like to introduce yourself?

**Ashlyn Saltzburg (02:27):**

Sure. Hi, I'm Ashlyn Saltzburg. I'm 15. I live in Los Angeles, and I have Crohn's disease.

**Amber Tresca (02:36):**

So, I wonder if you would tell me about Ashlyn's diagnosis of Crohn's disease, such as when her symptoms started, what that process of getting diagnosed was like for you, and what it has been like for your family.

**Ashlyn Saltzburg (02:48):**

I was eight years old, and every day, every week, it sort of just started building up. It gradually just got worse. It started at school, when I just frequently just had the urge to use the restroom. So, I would miss a lot of class, and obviously I was younger, so I didn't know what was really going on. I just thought everything was normal. And so, a couple weeks later, we went on a trip to San Francisco, and it's about a six-hour drive, and at every rest stop I had to use the restroom. So, that was not ideal. And so, we had to cut our trip short because just my symptoms were just starting to get worse, and I actually had to go to the ER in San Francisco. But, they didn't give us any result. They had no diagnosis.

**Ashlyn Saltzburg (03:52):**

So, we saw multiple doctors. One said it could've been a stomach bug, which it obviously wasn't. Some others had misdiagnosed it. So, eventually, we see Dr. Rabizadeh at Cedars-Sinai, and he recommended a colonoscopy and endoscopy. And so, that resulted in Crohn's disease.

**Amber Tresca (04:17):**

Kelly, what did you think when this was going on? You guys were on this trip, and poor Ashlyn was in the bathroom, and then the symptoms weren't going away. You probably did think stomach bug at first, right? But then after a few days, it's like, well, that's not what's going on here. What did you think?

**Kelly Silk (04:30):**

Yeah. We took her to her pediatrician and we asked him, and he said, "Oh, it's a stomach bug." And we said, "Well, can you do a stool? Take a stool sample?" And he's like, "Oh, no, no." He kind of poo-pooed it. And then when we went up to San Francisco and were like, "Okay, there's something not right here." She's just every rest stop, she's going to the bathroom. They were bloody stools. And then, when we got to the hotel the next morning, she was screaming from the bathroom, and I went into the bathroom, and the entire toilet bowl was full of blood. And, we contacted my dad who's a physician, and he is like, "You need to go to the ER." His diagnosis, he was not a gastroenterologist, but he thought she might have some form of IBD. It was very scary. We were just at a loss. We didn't know.

**Kelly Silk (05:27):**

So, when we finally Dr. Rabizadeh, who's a pediatric gastroenterologist, and he's the director of IBD at Cedars-Sinai, that it was like a godsend. He knew exactly what he was doing, knew all the steps. He took great care of Ashlyn. But I was frightened the whole way, and from the colonoscopy and the endoscopy, I was a nervous wreck. She started with infusions, as you know. And that was the other thing. I was bawling. I was hysterical because she was getting these infusions and they were sticking needles in her. But Dr. Rabizadeh was... He wasn't cavalier about it, but he was just like, "You'll get used to this. It's not going to be a big deal anymore."

**Kelly Silk (06:21):**

And then, Ashlyn would go in for appointments, and she was fine every time she had her infusions. She was sticking her arm out. She knew the routine. And it allayed a lot of my fears because Ashlyn seemed to be okay with it, and the medicine was working at the time.

**Amber Tresca (06:40):**

Ashlyn, as you're listening to your mom describe your symptoms and what went on during those times, I have a 12-year-old daughter, I once was a young girl, so I'm thinking about talking about these type of symptoms and how they could affect you emotionally. How does it feel for you to talk about it or to hear your mother describe that period of time in your life?

**Ashlyn Saltzburg (07:08):**

It kind of brings back a lot of nostalgia. It was a very scary time. I was young, so I didn't understand it, but I had a flare up during the pandemic, so I was very scared to go out of the house. I was always at home obviously because of the pandemic. But, I felt like I isolated myself, and I really understood my feelings of what it was like to have a flare up because I hadn't had one in like five years. So, it was all just crying every day. It was very emotional because I forgot what it was like to be, I would say, ill.

**Amber Tresca (07:51):**

Yeah, it was difficult when it all came back around again.

**Ashlyn Saltzburg (07:53):**

Yeah.

**Amber Tresca (07:53):**

Right? Yeah. Ashlyn, what has having Crohn's disease been like as far as your social life, and as far as your friends are concerned? Do your friends know about it, or do you talk to them about it?

**Ashlyn Saltzburg (08:06):**

I don't talk about it all the time, but it does come up frequently, especially we want to go eat, and they're like, "Hey, you want to have popcorn?" "No, I can't have popcorn." So, I feel like I just laugh it off sometimes. Sometimes people have to understand that when I'm around

friends and I have to go to the bathroom, it's not like we can wait five minutes. I have to go. Sometimes I just hope people are a little bit more understanding sometimes, because sometimes it just feels a little bit awkward to interrupt, but I have to and say that I have to go to the bathroom.

**Amber Tresca (08:55):**

How do you think that your friends or other people in your life could support you in your journey?

**Ashlyn Saltzburg (09:01):**

I think that obviously being understanding. I think that a lot of times I think to myself that they don't acknowledge it, so I feel like just knowing that they're there for me, and they always, at least, think about it sometimes, because a lot of times they don't know what's going on, not at school, because I used to leave early at school. Actually, this was every week, a lot of time, just leaving to go to my infusions, and a lot of times, like, "Where are you going?" I'm like, "I'm going to the hospital." So, it's kind of awkward because sometimes... There's sometimes people that I just don't want to know. Sometimes I just want people to understand that sometimes my health comes first.

**[MUSIC: About IBD Transition]**

**Amber Tresca (10:20):**

I'm excited to tell you about my partnership with a product I use every day. I started talking AG1 because I was taking all these supplements in pill form and it wasn't working for me anymore. Honestly, I would forget to take them, and it was also sometimes hard on my stomach. Now I've been using AG1 for several weeks and I love it. It doesn't have a medicine taste, but it has this mild tropical taste that I actually look forward to each morning. If you follow me on the Instagrams, you know that we like to go on family trips, and the travel packs are super convenient to bring with me.

**Amber Tresca (10:51):**

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**Amber Tresca (11:29):**

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**[MUSIC: About IBD Transition]**

**Amber Tresca (12:19):**

We're here to talk about the Restroom Access bill. So, you've been working with your assemblymember, Dr. Akilah Weber, to get a form of this law passed. Can you tell me how that process started and what set you on this path?

**Ashlyn Saltzburg (12:33):**

There was one instance back at the beginning of the pandemic, we went to go see my grandpa in a living facility, and they didn't let people in because it was obviously the beginning of the pandemic. No one knew what was going on. So, we couldn't even go in. And so, all of a sudden, I had to use the bathroom. And this was the first time that I was really outside of the house since March. So, obviously I hadn't had an urge to go. I was just inside my house, right near the bathroom, right next to me. So, obviously, they didn't let me in.

**Amber Tresca (13:15):**

Oh, no.

**Ashlyn Saltzburg (13:15):**

Even though I showed them my card and I told them. We tried... I believe it was a 7-Eleven a block away. Did not have a bathroom. Then, we ran to a hotel two blocks down. Unfortunately, I had an accident because I couldn't... It was really bad. My flare up was so... It was just so terrible at the time. And so, I just couldn't make it. I was in so much pain. I was crying for help. It had to come out.

**Amber Tresca (13:58):**

Yeah. Yeah. I live with ulcerative colitis. I understand. I know how that goes. I'll tell you, every single person I know or that I've ever spoken to or interviewed with IBD, something like that has happened to them. So, that is why so many states, people who live with IBD have worked towards getting restroom access bills passed in so many different states because you go into the 7-Eleven... There is a bathroom in that 7-Eleven. We know that there is. There's an employee there who needs to use the bathroom, right? We know that's there. So, the fact that they won't let you use it in an emergency just doesn't make any sense, and for you to have to go through what you did, Ashlyn, that absolutely is horrible, and that shouldn't happen.

**Amber Tresca (14:43):**

So, then, how did this translate into you thinking about legislation and then working with Dr. Weber?

**Kelly Silk (14:51):**

Well, that was the impetus. That incident was the impetus for us. Ashlyn came to me and said that, "This is odd. I never experienced this before." But she's always been close to a bathroom because she's been at school or at home, and she never had thought about it before. And so, she said, "There must be something that we could do. Isn't there a law or something?" And I said, "Well, we have the IBD cards." So, we were just looking on the internet, and we came across this Restroom Access Act, and then we read the story about Ally Bain, and we read her story about how she got it passed in Illinois.

**Kelly Silk (15:39):**

So then, we were searching and trying to determine whether California had the same act, and we couldn't find it anywhere. So, with that, we decided to contact several assemblymembers as well as state senators. It was a very arduous process. I'll let Ashlyn speak to it.

**Ashlyn Saltzburg (16:04):**

Oh, okay. Since 2019, we wrote to or had a meeting with Senator Holly Mitchell, the 30th Senate District, and met her district representative in her office. Then, State Assemblymember Sydney Kamlager, and then Melanie Moreno of the California State Committee on Health in Sacramento, then the Business Professions and Economic Committee in Sacramento. Then we forwarded twice to different staff members who never got back to us. Then, Senator Alex Padilla, and Congresswoman Karen Bass for guidance, and then 40 senators.

**Kelly Silk (16:57):**

Ashlyn drafted the letters, and then I'd tweak them, but we just did a blast. We actually did it the old fashioned way, I should say. We mailed them, but we mailed letters to 40 state senators, and then a handful of assemblymembers. And after that, we were like, well, we'll give them to such and such date to respond. We waited and waited and waited, and of course we heard crickets, and decided, well, I guess we have to reach out to them.

**Kelly Silk (17:35):**

So, Ashlyn and I called as many senators that we could, and we actually were able to... After numerous calls, we were lucky enough to reach out to the State Senator Newman's office, and his legislative aide was terrific. He said that he talked to his senator, and his senator thought that it should pertain not just to people with IBD, but it should be for all people. So, he said that would actually make it more difficult. And then, the senator had a concern about the business committee objecting to it, and there's no fiscal issue with respect to the bill, or fiscal responsibility. There may be a liability issue, perhaps, but not a fiscal one. And then, Senator Newman's legislative aide contacted me and said, "You know what? The senator wants to pass on the bill." That was a real blow to us because we had been working with him in tandem for about a month and a half.

**Kelly Silk (18:56):**

So, he then found out about, I'm sorry, Assemblymember Weber, and he told us that she actually penned the bill for Restroom Access Act. So, we immediately got on the phone with her. We spoke to her district representative. We sent him a letter also and explained our

situation and how we wanted to be really engaged in the process. He was like, "More the merrier." With that, Ashlyn said she wanted to provide her testimony, because the bill is drafted. It was going before the business committee. So, they said that they would allow Ashlyn to virtually provide her testimony. So, Ashlyn testified before the business committee. It actually passed. And then, it went to the health committee.

**Ashlyn Saltzburg (19:53):**

And then it went to the health committee actually a few days ago, and it actually passed. So, we had a couple of letters of support. So, first, my doctor, Dr. Rabizadeh, the Director of Pediatric Inflammatory Bowel Disease Program at Cedars-Sinai, and then Stacy Dylan, co-founder and board director of Connecting to Cure Crohn's and Colitis.

**[MUSIC: About IBD Transition]**

**Amber Tresca (20:21):**

So, you had a lot of support in getting this bill to where it is now. I'm not familiar at all with how that all works in your state. So, it's been through committee. Does that mean it next goes to a vote?

**Kelly Silk (20:34):**

What happens is... Okay, so it's first with the state assembly, so it goes first, as we said, to the business committee. Then the health committee, and then it goes to the appropriations committee, and then the assembly votes for it or against it. And then it goes to the state senate, and it goes to their business committee and their health committee, et cetera. And if it passes the senate, then it goes to the governor's desk. That would probably be in late September that the governor would review the bill. We did actually have a meeting with Assemblymember Weber, so that was very interesting too.

**Amber Tresca (21:20):**

So, she already had some language around a bill, and then you contacting her was something that was helpful to her, I guess, in pushing this forward and getting it through all of the committees?

**Kelly Silk (21:33):**

Yeah, I think so, because Ashlyn provided her testimony, and we told her that we would be interested in tweaking any language, wordsmithing the bill. Her office has been very good about keeping us in the loop and letting us participate in any way we can. It seems like such a tedious process when she told us all the committees that we have to go through, and it just sounded so exhausting, but when she said that by September it goes to the governor's desk, it didn't seem like that long.

**Amber Tresca (22:11):**

So, it sounds very hopeful at this point.



**Kelly Silk (22:14):**

I hope so. Yeah.

**Amber Tresca (22:37):**

Ashlyn, what do you think this law, if it's passed, in California, what do you think the effect would be for people who live with a digestive disease such as you or anyone else?

**Ashlyn Saltzburg (22:50):**

I think we wouldn't have as many worries. I feel like it would be a lot more calm, because when I'm in the car, the only thing I worry about is where the restroom is. So, I feel like I will just be more relaxed, less anxiety, especially after so much anxiety I have because when I get rejected to use the bathroom, I have so much anxiety, I get very, very nervous, because all of a sudden I just feel like it's coming. The urge gets even worse at the moment. So, I have to run somewhere else. So, I feel like I will just have less anxiety. I'm not going to have to worry about it.

**Amber Tresca (23:40):**

Right. I feel like if you have less anxiety, then you will probably not need to use the bathroom. Do you feel that way?

**Ashlyn Saltzburg (23:47):**

Yeah.

**Amber Tresca (23:47):**

Yeah, yeah. What was that like to give your testimony? Because it's very emotional. It's difficult. You're describing things that a lot of people don't like to talk about at all. How did you feel giving your testimony?

**Ashlyn Saltzburg (24:00):**

Well, at first, funny story, they gave us the wrong number. Everybody had the wrong number. So, at first, they called my name multiple times, and so then I didn't get to speak at first. We contacted Assemblymember Akilah Weber, and we also contacted the business committee. And so, finally, they kept in touch with us, and they said they can come back to us and speak at the end. So, when I finally did, I just felt so relieved because I wanted to speak. I was crying. I wanted to speak because I wanted to be a part of it. I wanted to have a say, because this was my experience and I wanted it to be passed.

**Amber Tresca (24:42):**

It's very courageous. Remind me again how old you are, Ashlyn.

**Ashlyn Saltzburg (24:46):**

15.

**Amber Tresca (24:47):**

15. I cannot imagine talking about these things in front of your state assembly at the age of 15. I was diagnosed at 16. I don't think I told a soul what was going on with me. So, I'm in awe of you, and what you're doing is really amazing, and I applaud your courage. And for that reason, I want to make sure that people can help you. So, you've gotten some support. It sounds like the ball is rolling here. But we want more. We want people to know how they can help you. So, what are some ways that a person who's listening right now could help you in support of getting the Restroom Access Act passed in California?

**Kelly Silk (25:33):**

The first thing is, is that, I guess we would need more letters in support of the act. Also, providing more testimony from different organizations, from committees or individuals, is another way that they can bring more support to the bill.

**Ashlyn Saltzburg (25:53):**

Also, you can just join and listen to the committee, because it's just helpful... You can just gain knowledge, I guess. That's just one tiny little thing of support. And also, if you just join... At the end, I believe they ask if there's anybody on call that's in support, and you can just say your name. Just say that you support it. It's not a big deal. You're speaking for two seconds.

**Kelly Silk (26:21):**

I guess there's a difference between sponsoring and supporting, and what we were having difficulty with, with all these senators, is that we couldn't find a sponsor. If there's anyone who would step up to support that, that would also be another way to enhance the bill.

**Amber Tresca (26:43):**

What kind of entity would support you in this? A nonprofit? Patient advocacy groups? Is that the kind of thing that you're looking for?

**Ashlyn Saltzburg (26:50):**

Yes.

**Kelly Silk (26:51):**

Yes.

**Amber Tresca (26:52):**

All right. Just so that I understand. I'm learning all of the time. I still don't know so many things. The idea that these bills have to go through so many committees is just... it's staggering to me. Sometimes I wonder how anything gets done. And, maybe that's why this hasn't been done already.

**Kelly Silk (27:06):**

It's true.

**Amber Tresca (27:07):**

Well, thank you so much for all of the work that you're doing in this. I hope that you all, though, have some things coming up that are more pleasant. So, do you have any summer plans? What's going to happen after you get out of school, Ashlyn?

**Ashlyn Saltzburg (27:22):**

I'm going to Colorado with my grandparents.

**Amber Tresca (27:25):**

Nice.

**Ashlyn Saltzburg (27:26):**

Finally getting away from my parents.

**Amber Tresca (27:28):**

That's so funny. What are you going to do in Colorado? Do you have a lot of outdoor stuff planned, do you think?

**Ashlyn Saltzburg (27:38):**

Yeah. I know that there's a lake, so we can go fishing. I usually go there in the winter.

**Amber Tresca (27:45):**

Oh, okay.

**Ashlyn Saltzburg (27:46):**

So, I usually ski, but I'm excited to go during the summer.

**Amber Tresca (27:52):**

And, is your Crohn's disease behaving lately? How are you feeling?

**Ashlyn Saltzburg (27:56):**

Right now, I'm saying that I'm okay. I wouldn't say that it... how it was like before the pandemic, but I'm not going to say that it's how I was when I was diagnosed.

**[MUSIC: IBD Dance Party]**

**Amber Tresca (28:10):**

Ashlyn, you're so courageous. And I am really appreciative, and I admire everything that you have been doing to get this law passed in California. I think it is really important, and I look forward to seeing what you're going to do next. So, thank you so much, Ashlyn, thank you so much, Kelly, for coming on and for telling your story. And we're going to do what we can to get more eyeballs on this and get you more support in California to get the Restroom Access Act passed. Thank you.

**Ashlyn Saltzburg (28:37):**

Thank you.

**Kelly Silk (28:39):**

Thank you very much, and it was lovely to be a part of this.

**Amber Tresca (28:48):**

Hey, super listener. Thanks to Ashlyn Saltzburg and Kelly Silk for sharing their story and for the work they're doing in California to champion the Restroom Access Act. It has been a long road to get this legislation moving, and as you heard from Ashlyn and Kelly, it took significant effort on their part as well as from Assemblywoman Dr. Akilah Web, Ashlyn's gastroenterologist, and patient advocacy group Connecting to Care Crohn's and Colitis. I'm going to put information in the show notes for you to read the bill or to contact the sponsors to give your support and to follow the progress. Links to a written transcript, everyone's social media handles, and more information on the topics we discussed is in the show notes and on my episode 119 page on AboutIBD.com. You can follow me, Amber Tresca, across all social media as AboutIBD. Thanks for listening, and remember, until next time, I want you to know more about IBD.

**Amber Tresca (29:48):**

About IBD is a production of Mal and Tal Enterprises. It is written, produced, and directed by me, Amber Tresca. Mix and sound design is by Mac Cooney. Theme music is from Cooney Studio.

**Amber Tresca (30:03):**

Did you do a podcast at school? What was that like?

**Ashlyn Saltzburg (30:06):**

We had made one for health class. It did turn out great, so we got a good grade on it, so...

**Amber Tresca (30:12):**

Oh, nice, nice. Do you want a job? I can use some help.

**Kelly Silk (30:20):**

I think you're doing all right, Amber.

**Amber Tresca (30:20):**

Thank you.