

About IBD Podcast Episode 105

What Remission Means to a Teen With Ulcerative Colitis

Inflammatory bowel disease (IBD, Crohn's disease, ulcerative colitis, and indeterminate colitis) is being diagnosed in young people with greater frequency. Research on how to treat pediatric patients, and indeed how to prevent IBD in the first place, is still lacking. What's not in short supply is the strength and resilience shown by pediatric IBD patients and their families. Meet Brooke, a pediatric patient at Connecticut Children's Hospital who credits her dedicated IBD team with her ability to live a life filled with summer camp, dance, and tennis lessons, without the symptoms of ulcerative colitis.

Concepts discussed on this episode include:

- [Camp Oasis](#)
- [Bradley S. Jerson, PhD, Pediatric Psychologist](#), who appeared on [Episode 77](#), [Episode 78](#), and [Episode 99](#)
- [About IBD Podcast Episode 27 – Welcome to Camp Oasis](#)
- [Why Clinical Remission Is Not the Goal in IBD](#)
- [Avoiding Dehydration](#)

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[MUSIC: About IBD Theme]

Amber Tresca 0:00

Real quick before we get started, don't forget to check the show notes for more information and a transcript. If you enjoy this or other episodes, please do me a favor and leave a rating or review in your podcast app.

Amber Tresca 0:16

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.

Welcome to Episode 105!

IBD is sometimes called a disease of young people. When Crohn's disease, ulcerative colitis, or IBD unspecified, are diagnosed in children under the age of 6 years, it's called "very early onset

IBD” and when it’s diagnosed in those under the age of 2 years, it’s called “infantile-onset IBD.” IBD in younger patients may be more difficult to treat and, as you can guess, there isn’t enough research to understand how best to help these patients and their families. In addition, the diagnosis of IBD is rising all over the world and especially in kids.

My guest is Brooke, a teenager who lives with ulcerative colitis. I met at Connecticut Children’s Pediatric Infusion Center. Before she received an infusion of her IBD medication, she sat down with me for a few minutes to tell me about her experiences as a pediatric IBD patient, how Camp Oasis has been important to her life, and how the comprehensive care she receives at Connecticut Children’s has made all the difference.

Amber Tresca 1:33

So Brooke, thank you so much for coming on About IBD. I really appreciate your time.

Brooke 1:38

Thank you for having me.

Amber Tresca 1:39

We are here today because you're getting an infusion of your medication. And I'd like to know maybe just really quickly what age were you when you were diagnosed with IBD?

Brooke 1:50

I was diagnosed with colitis when I was one and a half.

Amber Tresca 1:54

You were one and a half.

Brooke 1:55

Yeah.

Amber Tresca 1:56

Oh my gosh, you don't remember it now? Oh, my goodness. Okay. And how old are you now?

Brooke 2:01

13.

Amber Tresca 2:02

Oh, my gosh. So your whole life you've been, you've been dealing with this?

Brooke 2:07

Yeah.

Amber Tresca 2:08

What has it been like to go to school with IBD? What was it like when you were really little? Was there anything that was different about you, you're going to school than it was for your friends?

Brooke 2:19

I mean, I missed a lot more school. So like, especially for math classes. I had to like catch up on a lot of work. And I had like a lot of like, and I had infusions of doctor's appointments. So then I would have to like, I'd have to do like more tutoring, more worksheets to catch up.

Amber Tresca 2:38

And how was it with your friends? Did your friends think that that was kind of awesome. I know, when I was a child. And when I was a teenager, I was diagnosed when I was 16. I had lots of times when I was out of school for a long periods of time. And then I had a tutor that would come to my house. And my friends thought that was awesome. I didn't really like it. How did you feel about that?

Brooke 2:59

I mean, I didn't really tell like my friends. And I was younger, because I like that was like really bad. So I was like being very secretive. But like I would say like I have to like I was busy. So I wouldn't be able to do some things. And they thought that it was like, they didn't really think it was like they didn't make any comments.

Amber Tresca 3:17

So do you miss school sometimes because you have infusions, or you have doctor's appointments?

Brooke 3:23

I'm not really I mean, I was missing a lot more school and I was younger than now. Now it's more like, I've only like once in a while.

Amber Tresca 3:31

Do you think that's because your IBD is better controlled now than it was when you were younger?

Brooke 3:37

Yeah, I think that it's like, it's like, much better than when I was younger.

Amber Tresca 3:42

Yeah. And do you, do you do any sports, by the way?

Brooke 3:46

I don't do any sports. I mean, I do like, dance. I'm doing tennis.

Amber Tresca 3:52

You don't think dance and tennis are sports?

Brooke 3:54

Well, no, it's like some people think like the dances. I don't really think dance is a sport. I think it's like an active activity. I don't, it's like exercise. Probably it could be just as much exercise as you get for doing some other sports. Maybe not. But like, depends on what sport you're comparing it to. But like, I don't think it's like really a sport.

Amber Tresca 4:16

What kind of dance is it?

Brooke 4:18

I do like a bunch of like contemporary jazz hip hop.

Amber Tresca 4:22

Wow, that's amazing. And so you're feeling well enough to do these things?

Brooke 4:28

Yeah, I mean, I've just like much better like over the past like, two, three years? Or is it like Yeah, I think like two years, I've been able to do like, way more things and like, my disease isn't really acting up. So like, I won't like have to stop what I'm doing to like go to the nurse.

Amber Tresca 4:45

How has middle middle school -- and so Middle School was sixth, seventh and eighth grade for you. And how has that been as far as dealing with your IBD? Is it still the same? People don't really know what you're dealing with?

Brooke 4:57

Yeah, it's like, I mean, it's much more that's different than when I was younger. Because like now it's like, if people know about my disease, it's like, I'm like, I'm happy to open up. And it's also like, it's not. It's like, I barely have to go to the nurse. And yeah, I have to, like, really worry as much.

Amber Tresca 5:18

Do you ever start conversations about your disease? Like, how does it come up that you would tell a friend about it, for instance,

Brooke 5:25

So like, if it's like a friend that I'm, like, close enough or close friend that I wouldn't like mind telling. I'd probably like say, like I say, like, if like, I go to the nurse every once in a while, or like, when I can't, like meet up with them. Like, like, sometimes like my they would ask why then I would just like, say like that? Well, I can't because I've infusion or have a doctor's appointment. And then if like, took a new friend, then I'm just telling them, I would probably like start the conversation because I feel like they have a right to know.

Amber Tresca 5:56

You feel like they have a right to know? Because so you don't want to, for instance, come up with an excuse that maybe wasn't the truth. Is that how you're looking at it?

Brooke 6:07

Yeah, but like, it's like sometimes if it's like, something that's like, it doesn't really affect them. Like if it's like, if I keep on making up like excuses, and I feel like I should tell them the truth. But if it's like, feel like I should like, sometimes it's like, I felt like I have to tell them that I will.

Amber Tresca 6:25

What about adults? Do you ever tell adults or have a conversation with adults other than when you're receiving an infusion and a strange other IBD patient asks you a lot of questions with a microphone in your face?

Brooke 6:39

Well, like I don't really talk to adults that much. Yeah, except for like, my mom's friends. And I don't even know if like, my mom says anything. Like I'm sure like, I think that like, they'll ask me to like my like, aunt will ask me how my infusion were like my grandparents. And like that, I'll talk to him. But it's not really like, I'd be like fine, telling them just doesn't really like, come up. So I don't talk to them, like without my mom. So it's like,

Amber Tresca 7:08

Sure, yeah. Yeah, I get that. I understand that. Yeah, as a mom, I think what you do is you try to protect your kids a lot. So you might try to protect your kids from having to talk to people talk to other adults about, you know, the realities of living with IBD. Because it's not always, you know, fantastic.

Amber Tresca 7:29

What kind of questions do your friends ask you? Do they have any questions?

Brooke 7:33

I mean, like, they usually ask, like, if it's like getting better, which is like really sweet. They then they like, they asked like, well, how I've like been lately? They asked like, like, if there's like when I'll get like, better like or like, do I still have to like go for infusions? Will they explain infusions to them? And like, it's usually not like all the specifics. It's more of like the you know, are you get better?

Amber Tresca 8:01

Do you find yourself explaining the idea that you're better you're doing well now, but that this is something that's ongoing, and that it's, it's not really like a cold? You know, do they do they get that part of it?

Brooke 8:14

Yeah, it's like, I mean, I think that they get it I just like say it's like unactive, but it's still there. But it's like, what's it that I say that how I'm really lucky then I also explained how some people aren't as lucky because I feel like it's like, not a lot of people. Like, they probably just think that oh, if this is like, if my disease like, like everybody else has to like, if like, if mine is good that everybody else that has like colitis or Crohn's is also good. And that it's like I feel like they should know.

Amber Tresca 8:43

So you try to sort of put it in perspective in terms of the fact that I'm doing well now. But do you say things like, Oh, this is actually a pretty serious disease. I know kids that are, are worse off that type of thing.

Brooke 8:54

Yeah.

[Music: About IBD Piano Transition]

Amber Tresca 9:09

The Crohn's & Colitis Foundation has a summer camp for kids with IBD that's called Camp Oasis. It's a residential camp that's run by dedicated volunteers, including physicians, nurses, and other health care professionals who are available on site, 24 hours a day. Brooke has been able to attend Camp Oasis for several years. As she gets older, she's looking forward to participating in the LIT program, which stands for leaders in training. LITs are older teens who are given training to assist the Camp Oasis counselors with the younger campers.

Amber Tresca 9:42

How many years have you gone to Camp Oasis?

Brooke 9:45

Just a couple. I think like How many say...I think like next year will be with my six right, yeah.

Amber Tresca 9:59

Wow. And is it your favorite week of the year? This is what everyone tells me.

Brooke 10:04

Yeah, it's like I really miss it. It's like a huge family.

Amber Tresca 10:09

Yeah. Do you think that you ever would have met or made friendships with other kids who live with an IBD if you hadn't gone to Camp Oasis?

Brooke 10:20

I mean, it would be like, probably like a coincidence. Like, if I just like happened to but like, there's not like many people that go to my school that I know that have colitis, or Crohn's. I

think they're like, probably like, three that I'd know. That actually though, I think like one other that I know of, they're probably more than just, you know, they haven't like, felt comfortable tell people. Like I wouldn't tell strangers either. So they feel like can police. It's just like, I've met like, a lot of a lot of people at Camp Oasis. And there's like a bunch of people like of all ages. And it's like, I have friends who are like, like that were like, LITs when I was like eight. So it's really nice to have like different age groups. And then they always are like, comforting me when I felt sad.

Amber Tresca 11:07

Leaders in training. So are you going to be a leader in training?

Brooke 11:11

Yeah, well, once I'm older.

Amber Tresca 11:13

Once you're a bit older.

Brooke 11:14

Yeah.

Amber Tresca 11:15

Do you think that you'll continue? What about when you are not of the age that you'll be a camper anymore? Do you think you would come back and volunteer as a counselor or another capacity?

Brooke 11:27

I really want to be like a counselor, because it's good. It's like, I miss it so much. And it always like, be there.

Amber Tresca 11:33

Yeah. How do you keep in touch with the kids that you've met there throughout the year?

Brooke 11:38

So like, at the end of two years ago, at the end of camp, we got everybody's like phone numbers and like emails. And then we met with a group chat. And then there's also I don't know where it was, it was like a reunion. And so then there's like, a reunion. And then there's like five people who live near the place where it happened. And then we all like, had like a group chat. And then we all had like, not like a party, like get together. after.

Amber Tresca 12:10

Well, so friends for life, right? That's what it sounds like. Yeah.

Brooke 12:15

Four years, three years.

[Music: About IBD Transition]

Amber Tresca 12:24

At the time we talked, Brooke's ulcerative colitis was stable. However, that wasn't always the case. She and her family worked together with her team at Connecticut Children's to bring her disease under control. In fact, she was doing well enough that she attended a residential summer camp with healthy kids her age. Not only that, but she was able to use the skills she learned while working with her pediatric psychologist, Dr Brad Jerson to participate in activities that were out of her comfort zone.

Amber Tresca 12:52

And your friends at school? Do they sort of check in with you and ask you how you're doing every so often?

Brooke 12:59

I mean, yeah, it's like, it's only really like, every five weeks, like, you know, whatever. Like, I tell them like I can't, I'm busy. Then it's only whenever like, I say, like, I'm busy. They're like, and then I tell them why. Like, if I'm going for infusion, they'll be like, Oh, is it getting better? It's just like, it's like, not often, because it's like, they know it's inactive. Right? So every once in a while.

Amber Tresca 13:27

How do you think your symptoms are right now? Like, if you had to say that they're, they're good, better than they used to be?

Brooke 13:33

They're like, way, way better than they used to be way way better. Like, like, like, barely have any symptoms.

Amber Tresca 13:39

Wow. That's amazing. So what are you thinking about as you go into eighth grade, I have a son who just completed eighth grade, and he's going into high school. And wow, the amount of choices going into high school trying to figure out the classes that you want to take. Have you thought about that at all?

Brooke 13:58

For when I'm in high school?

Amber Tresca 13:59

Yeah.

Brooke 14:00

I mean, like, probably should. Now I will. Yeah. Like, I don't know. I probably want to take like some, some math.

Amber Tresca 14:15

Some math.

Brooke 14:16

Yeah. I don't know what the classes are.

Amber Tresca 14:18

Really?

Brooke 14:18

Yeah, sure. Yeah.

Amber Tresca 14:21

Oh, I want to talk about this. Do you like math?

Brooke 14:23

Yeah, but like, I like math and science. But like math is like really hard for me when I was younger. And math is still like my worst subject. But it's like, I still really like it because I want to get better at it.

Amber Tresca 14:36

Wow, that's fantastic. I love this outlook. Do you think that living with IBD has sort of helped shape that in you because I would say that you're sort of going towards the thing that you that is difficult for you and that most people would go away from that thing?

Brooke 14:53

Yeah, I think that's like, it has like also made me stronger and it made me like more like resilient. Like I could do anything. So if I could handle like, getting IVs and if I can handle like what happened with me, I was like, way younger than I can be able to like, like do anything if I like, put my mind to it.

Amber Tresca 15:21

Would you say that you're fearless?

Brooke 15:24

Maybe? I mean, different things. Yeah.

Amber Tresca 15:30

What is something that you've done recently that you found scary, but you did it anyway?

Brooke 15:36

So like I did this activity, and probably no one knows what it is. It's like circus, but like, we had to do like, like foot tricks almost. And I was hanging by my foot. And then like, and I had to let

go. So like, if my foot came out, then I was like, really hurt my head. And so I was really scared. And then we had to do like the performance and had to be in sync with everybody. And I was like, in the front. So I was really scared. But like, I still did it.

Amber Tresca 16:08

Right. Yeah, no, that's amazing. And let me ask you this, too, because doing performances, doing things like that, especially when you have ulcerative colitis, that's a lot. Not only is it getting up on stage and doing those things in front of other people, but you are living with a disease that might you know, you might need to take a break for a minute. So I think that's really fantastic. How has that been? You're well enough that it's not, that's not an issue for you anymore.

Brooke 16:35

Yeah, it's like, also, like, the best thing is like tap water. And because it's like, it was really hot at camp, it was like, everybody had to get hotter for like, water break. So it wasn't like, and I didn't really tell everybody, because I didn't really feel comfortable at camp. But it was like, wasn't even like, I wasn't feeling like, my stomach hurt in the middle of it, which is like really good. And I kept myself distracted. Whenever I did, like, if I ever did a symptom did come up so and like that was activity that I really enjoyed. I can't. So I was like, can I just get a focus on this. And like, distract.

Amber Tresca 17:13

How did you learn how to put yourself in that frame of mind that you could do that. And you could distract yourself from what was going on with your physical body?

Brooke 17:22

Well, Dr. Brad like, so he taught me like a lot of meditating. And I also like, like my mom, she said to like, distract yourself. And then the activity I would do when I was younger, like art because I didn't have like, my stomach hurts. And then I would just like I didn't want to do any actually, like sports or activities like that. But like, I just decided that like it actually did work. Like if I would just like, do it I'm doing and then the more I think about it, then it's not gonna really help because it's like, still gonna hurt. But if you're like doing something else, you're distracting yourself. You're just focusing on the activity instead of focusing on how you're feeling.

Amber Tresca 18:03

That makes a lot of sense. That's really great. Oh, I'm so impressed. You also play tennis. How has that been?

Brooke 18:11

I just started.

Amber Tresca 18:12

Wait, you started yesterday.

Brooke 18:14

Oh. No, I did like Yeah. But like, not really. That was like for like five days.

Amber Tresca 18:22

Uh huh. So what drew you to tennis? Why tennis?

Brooke 18:25

Well, my mom, she's like, she wants...she plays tennis. And she's like, basically a pro.

Amber Tresca 18:33

Oh, okay.

Brooke 18:34

She's a pro. And so she wants to be able to like play with me. It's a good activity during the summer. And, like, supposed to be like doing more activities this year, because we had like no activities last year. And yeah, it's also like, I actually really enjoy tennis because when I hit the ball, it's fun. Even though I missed the ball a lot.

Amber Tresca 18:57

Does Mom stand on the side? Mom is to my to my left. So she's listening to everything that I'm saying to you. But does mom stand on the sidelines of tennis and tell you how to do it? Or does she talk to you afterwards?

Brooke 19:10

So I have like a private instructor. Yeah. And so then at the last like five minutes she came which made me stressed. So then I was like, did poorly but I blame it on mom.

Amber Tresca 19:27

So So mom, we're finding out right here, mom that you should maybe not come to tennis practice. Is that what we're saying?

Brooke 19:35

So much better. Words there. I'm totally just

Amber Tresca 19:40

That's very funny.

[Music: About IBD Transition]

Amber Tresca 19:49

During the pandemic, many of us were reliant on social media or video conferencing to connect with our friends and family. Many parents are concerned about how to decrease screen time and get kids back to in-person activities. For people with IBD, social media is sometimes the

only way to meet other people living with the disease. Brooke deftly cuts to the chase about her relationship with social media and I think we can all learn from her example.

Amber Tresca 20:17

Brooke, do you use social media at all? Are you on social media?

Brooke 20:20

I mean, like, No, I don't have any I have like, text. That's not really social media. Yeah, it's like, I also don't have a phone. So it's also like, pretty good, because it's like, I like a lot of kids my age, they're like, a little more like, they like act like they're like, I don't know, a lot, lot older. That's why I noticed that camp. And they are like, they all are, like addicted to their phones, even though they have it. Like they had computers. And they would just like, go on tick tock, tick tock account. And I know and it's like, I feel like like, even when I'm on my iPad, it's like, I get so like, distracted. And it makes me like, more like sad and moody. Or, you know, whenever I'm on my, like, electronic too much. So it's feel like I'm actually pretty happy. They don't have social media, even though I want it.

Amber Tresca 21:10

I know. Well, it's kind of like fast food. It's like I want it. It's not gonna be good for me. Tomorrow, I'm gonna have a bad day. But right now I want it. Like I totally, I totally understand that. So on your iPad, do you watch YouTube? Is that a dumb question? Everyone who is 13 watches YouTube, right?

Brooke 21:28

I mean, I watched like, one YouTuber, but like, not really, because it's like, it's like, too much takes up like all your time on YouTube. And this YouTuber only posts like once a week, and a lot of them posts like, four times a week, right? So it's like, it's like a fun activity for me to do like, whenever like, I want like inspiration, or I want like, something to look forward to.

Amber Tresca 21:55

Mm hmm. That makes a lot of sense. Like, yeah, we used to have weekly TV shows. You'd have to wait all week for the show to come out. You know, you couldn't just watch a whole season in a day if you wanted to. So it's kind of a lot like that. I guess. You are a very impressive person, Brooke. I have to say that. It has been fabulous to talk to you. I really appreciate your time. Tell me what what kind of music are you listening to right now?

Brooke 22:24

Um, I was listening to Broadway a lot, especially like Hamilton, because it's like also like just a lot of fun to like, sing along. It's like my happy place.

Amber Tresca 22:35

Wow, that's so fun. Is there anything that you would say to another kid who just got diagnosed with IBD?

Brooke 22:43

Um, this is probably like, the most basic thing to say. But like, I think that it's like, it was like, it gets worse before it gets better. And it's just like, if you keep on pushing through and you have a positive mindset like that really helped me because my mom would be like, have positive outlook and then just keep on thinking positive. Distract yourself because that definitely helped. You might be like, thinking oh, now it doesn't but like, and also like drink lots of liquids like water. I don't think...anybody should drink like enough water. But yeah.

Amber Tresca 23:18

I know we just met today. So you don't know this about me. But I am famous for not drinking enough water. So thank you for that advice. I will take it to heart I will think of you from now on especially when it...see I have this giant thing of water right here that I should be drinking. Have not taken a sip of it.

Brooke 23:34

I had like a water bottle I supposed to drink because easier for the IV to go in. And I had like one sip.

Amber Tresca 23:41

Oh, we just totally ruined that.

Brooke 23:43

She's got like this huge water and she like drinking like less than an hour. So and she's like, drink your water.

Amber Tresca 23:50

Yeah, we all have to listen to our mothers. So Brooke, is there anything that you want to say to the people that have cared for you during your IBD journey?

Brooke 24:02

I think that our like, I'm really thankful for all like my doctors and nurses who like have gotten me this far for where I am. And where like I don't. It's like, I don't need to go to actually doctor's appointments. It's like, I'm like really healthy. And I'm really grateful.

[Music: IBD Dance Party]

Amber Tresca 24:17

Wow, that's amazing. Thank you so much for sharing your experiences with me it is really impactful for other kids, especially kids that don't have the benefit of something like a Camp Oasis to be able to hear the voice of another person that's like them, and also to the moms of kids like you because you have built extraordinary resilience. So I really am looking forward to hearing what you're going to do next. Thank you so much for your time, Brooke. I really appreciate it.

Brooke 24:46

Thank you for having me. I enjoyed it.

Amber Tresca 24:53

Hey, super listener. Thanks to Brooke and her family for allowing me to bring her voice and her perspective to about IBD. Extra special thanks to friend of the pod Dr. Brad Jerson who connected us and who works tirelessly every day to help families affected by IBD.

Amber Tresca 25:10

Links to more information about the topics we discussed is in the show notes and on my episode 105 page on about ibd.com If you are a family that's touched by IBD I'm inviting you to connect with IBDMoms, a nonprofit I co-founded with Brooke Abbott of the Crazy Creole Mommy Chronicles. IBDMoms is a space for moms and moms to be who live with an IBD and moms of kids with IBD to find help and support. You can find us as IBDMoms across all social media. You can also follow me, Amber Tresca, across all social media as About IBD. Thanks for listening.

Amber Tresca 25:46

And remember until next time, I want you to know more about IBD

Amber Tresca 25:52

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.

Brooke 26:09

I forgot the camp name. Okay...it was two years.

Amber Tresca 26:15

I can't tell you what I have for breakfast this morning. That's okay.

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