

## About IBD Podcast Episode 86 - Double Baggin' It With Joe and Danielle

### **Amber Tresca**

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 86. My guests are Danielle Gulden and Joe Teeters of Double Baggin' It. There's a few things you need to know about them: they're best friends, both of them live with an ileostomy, and they use humor to raise awareness of IBD and life with a stoma. Danielle and Joe speak and perform at various IBD and ostomy events, work to educate healthcare providers about ostomies, and travel to DC to tell their stories at Day on the Hill events.

As you might expect, we talk about their individual IBD journeys and how they met and decided to form a partnership, but also why they filled ostomy bags with pudding, their favorite poop stories, and why it is important to them that they work as advocates and activists.

Joe and Danielle, Double Baggin' It. Thank you so much for coming on About IBD!

### **Joe Teeters 1:14**

Thanks for having us.

### **Danielle Gulden 1:15**

We are super excited.

### **Amber Tresca 1:17**

So I always like to start out by asking people a little bit about their IBD journey. Both of you also have different kinds of complications. First, Danielle, I wonder if you would tell me a little bit about your ulcerative colitis story. And then Joe, maybe you can tell me what it has been like having Crohn's disease.

### **Danielle Gulden 1:33**

Um, so yeah, so I was a really healthy kid growing up until around the age of 16. So in high school, around junior year, I started having symptoms that we kind of brushed off as eating the wrong foods or drinking too much grapefruit juice, which was my favorite back then. So I just kind of started seeing my personality traits change with with an illness that kind of crept up, I started becoming a little less spontaneous and a little less fun.

And I somehow just powered through got to college, went to see a doctor, I was misdiagnosed for six years, unfortunately, with a gluten intolerance, which was not the most fun thing to have in college, because it was annoying and expensive. So we didn't have you know, all of the great natural food stores we have now. But I ended up starting with just a lot of the gurgling belly and bad diarrhea and always needing to know exactly where the restroom was.

That kind of changed over time into more serious issues with that, I went from just having a couple of bouts of diarrhea day to having really bloody diarrhea and go into the bathroom 25 to, 25-ish times a day, which was just altering my lifestyle altering school, altering everything about how I lived. And so I finally one of my doctors here in Columbus finally said, you know, this is really not normal, I don't feel like this is a gluten intolerance. And she sent me for colonoscopy. And lo and behold, I had a very severe case of ulcerative colitis.

And although it was scary to have a diagnosis was also really amazing to have a diagnosis because I didn't have to be. I just I felt like, you know, an answer is so good. So being able to start on treatments and not having like a, I was always fearful that it was something far worse. And so it was just really good to have a have that diagnosis, diagnosis back in 1999. And so it did took a good six years to get the real diagnosis, which thinking back on that just blows my mind.

**Amber Tresca 3:46**

Yeah, even during that time, you would think that it would have gone quicker than that. Were you able to still do theater when you were in college, even though you were so sick?

**Danielle Gulden 3:55**

I only did theater in high school. So by the time I was in college, I'd been feeling ill for a year or two. And I powered through it. But unfortunately, I went to Ohio State University, which is a giant campus, I lived far- very far from the classes that I had. And there were so many times I just didn't make it to class.

There's actually an instance where I had to I actually ended up going to school a little bit longer because I had to drop out of classes because the classes that I had were in older buildings and the restrooms unfortunately, were varied. So there was a male restroom on one floor and a female restroom on the next and of course mine was on the male restroom smack dab in the middle of a very big building. So I had to run down the hallway down to set of stairs and all the way back to the middle where the bathroom was and as anybody with IBD knows, urgency is such an issue and running can be detrimental. Right Joe never know what can happen when you have to run with colitis.

So on top of that, I actually ended up, because I was so ill, I ended up changing majors to a more safe major to have with an illness. So I went from environmental science, I wanted to be a national park ranger, do something with natural resources. And unfortunately, I was starting to realize that that was not going to be easy to do when you had to go to the bathroom 20-25 times a day. So I ended up switching majors in my second year and going for communications and marketing, which, you know, one would think is a little safer to have an office environment, which was the case, but it was very unfortunate that I had to change what I'd wanted to do my entire life because of diarrhea.

**Amber Tresca 5:40**

Yeah. Oh, my gosh, our stories are so similar that it's bonkers.

**Danielle Gulden 5:44**

Oh, wow.

**Amber Tresca 5:44**

It's it's really bonkers. I do have an environmental science degree.

**Danielle Gulden 5:48**

Oh, wow.

**Amber Tresca 5:49**

Because I never had that come to Jesus moment. Even though people told me, I just didn't listen.

**Danielle Gulden 5:59**

I had no idea. That's so cool.

**Amber Tresca 6:01**

Yeah, you know, could literally not do any of the things that I wanted to do, like, go into the Peace Corps and do all of that, No.

**Joe Teeters 6:06**

You're in the Poo Corps instead. Yeah.

**Amber Tresca 6:10**

We should have a Poo Corps. Oh, let's get t-shirts.

**Danielle Gulden 6:12**

Yeah, I like that. I'm in.

**Amber Tresca 6:14**

Thank you so much for your story. Danielle. Joe, why don't you tell me a little bit about your journey with Crohn's disease.

**Joe Teeters 6:20**

Growing up, I was always I always had poo problems. I was, I was a pooper. Nothing ever really rose to the level of clinical significance where my parents had to take me to the doctor or anything but the youngest of six kids, I was always in the bathroom, you know, Joe's pooping again, all that kind of stuff.

When I graduated high school, I joined the naval reserves. And while I was away for five months of training, that's when I started really kicking in having issues, symptoms, pain, lots of pain, cramping, and things got worse than what they had been in my previous life with like that bouts of constipation, diarrhea, the pain was the most significant issue that I was experiencing. Of

course, being away for Naval Training, basic training, there was certainly a high stress environment, being 18 years old as we're all away from home and then being in that in that environment. So when I got back, after my five months of training, my parents started taking me around to figure out what was going on because problems or the problems continued. So I started going around the doctor. And like Danielle, it took a while to get diagnosed, but nowhere near as long. It was about a year back and forth with a doctor until I finally had a colonoscopy, which confirmed that I had Crohn's disease, and that was at the age of 19.

And I started just like most Crohn's patients, IBD patients I started on back in 93 was before biologics. So I started on high doses of steroids, sulfa drugs, and so forth. And at the time, I was going to, after I finished naval reserves, I was going to school to study computer science. And I was going to school full time working part time, but once I was diagnosed with Crohn's disease, I needed to start working full time because I needed health insurance. So my plans kind of shifted there.

Because, because of that, and my disease was really bad at the time and actually looking at hindsight, I believe the actual trigger or the first significant event with Crohn's was probably earlier when I was 14, when I had an emergency appendectomy. And this is only looking back in hindsight, because I look at the symptoms, look how I was feeling, especially at that time. I think that might have been the first real sign of my Crohn's disease. So I started working, working full time, started my life change. I got a medical discharge from the naval reserves, which was it was, it was disappointing because I was really enjoying the the service that I was doing. I was the naval reserves as a CB construction battalion. I enjoyed that training. I enjoyed the people that I was working with there, and I was really excited to continue that.

But I couldn't, having Crohn's disease, did- my disease was really bad at that time. Two years later, from 93 to 95. I had had my first resection, and in the 27 years I've had Crohn's disease, I've had two resections and then my permanent ileostomy surgery, and 2012. Over that time, I've dealt with anemia really bad, I had lots of bleeding. With my, with my Crohn's disease, I had, had multiple blood transfusions. And but since my ostomy surgery, though, that's been way, way better. I have my hemoglobin state up. And so the ostomy is really a great thing for me on my IBD journey.

**Amber Tresca 9:40**

So how long were you in the naval reserves?

**Joe Teeters 9:42**

Almost two years from my enlistment date, because once I was diagnosed, I was diagnosed in February of 93. By that summer, June of 93. It's strange, it was funny kind of the way it happened. I popped for a random drug test on my regular Monthly drill. And I was freaking out because I'm like, I'm on all these drugs, I got to tell them. So I'm like, Yeah, I've taken, you know, Asacol. I'm taking prednisone I've taken imuran. And you know. And so that was on a Saturday show for drill. By Sunday, I had my discharge. Because I was diagnosed with Crohn's.

**Amber Tresca 10:21**

I'd like to know a little bit more about that process, if you don't mind, because it's always been my understanding that Crohn's disease and ulcerative colitis are two conditions that basically they tell you, no way. You can't be here, is that accurate?

**Joe Teeters 10:37**

It is. And I'll put a caveat in here I was 19 years old, I was overwhelmed with dealing with the Crohn's disease as it was, there were processes in place where I could have appealed the decision, what the decision was is when you have a diagnosis like that they they label you as unfit for deployment. So since you can't be deployed into overseas, into a warzone or anything because they can't guarantee that they'll be able to get you your life saving medication. So that was the decision of went into the decision. But I could have gone through some sort of appeal process and try to potentially get like a different job assignment or something that would have been always stateside, something that wouldn't put me in the position of being deployed. But I was 19. I was overwhelmed with Crohn's and trying to figure out my life. And I was just like, I guess I'm out. Alright.

**Amber Tresca 11:29**

Yeah. Oh no, that's completely understandable. I get, I get that. And especially during that time, when there was, I don't want to say more stigma, but maybe just a different kind of, of stigma and less understanding about IBD, in general. But through your diagnosis process, you weren't going through anyone that was involved in the military to get a diagnosis.

**Joe Teeters 11:52**

No, because as a reservist, it's not the same if had I been at UT, it would have been a lot different. I would have been going to the military hospitals and doctors, but as a reservist, I just show up once a month. Other than that, I'm a regular citizen.

**Amber Tresca 12:06**

Right. Okay. So you were going to your regular physician. So there was no, there was no connection there. Basically, you had to disclose, essentially.

**Joe Teeters 12:16**

Correct. And the only reason I disclose it, because I wasn't sure what was going to show up on the drug test.

**Amber Tresca 12:21**

Yeah, those drug tests are they really looking for, like what they really have been looking for? Like azulfidine or something?

**Joe Teeters 12:29**

You know, sitting here, 27 years later, more wisdom, but possibly I would have been just written it out and just said, All right,

**Danielle Gulden 12:37**

I can hear you. I take Tylenol, vitamins. Like you probably put literally every single thing. Vitamin D on my walk today. Yeah.

**Joe Teeters 12:46**

This morning, I had poppy seeds this morning.

**Amber Tresca 12:48**

That's so funny. Because I've had that experience. I don't know if you all have had it as well, where I had to go for a drug test for some job and had had a colonoscopy a couple days prior or whatever it was and had to disclose. Yes, I had a bunch of stuff. I don't even know what they gave me. And To this day, I don't even know if they test for that.

**Joe Teeters 13:07**

Well, and I'll say this also plays into it as well, just as like Danielle was saying with me listing everything off. One difference between Danielle and I is, I will say that I respect authority, but more like a fear of authority. Like I of course will toe the line. And all right, yes. Right. What do you say? Perfect, perfect Navy man. And Danielle, of course, would be like,

**Danielle Gulden 13:28**

I don't know what you're trying to say. We're best friends, we balance each other out very well.

**Joe Teeters 13:34**

I would say Danielle walks to the beat of her own drum, but there's no drum, she just walks.

**Danielle Gulden 13:42**

That's funny, and true.

**Amber Tresca 13:45**

I like that. As a rule follower and an institutionalist myself, I get you, Joe, I get that.

[MUSIC: ABOUT IBD TRANSITION]

**Amber Tresca**

So then tell me how you guys met.

**Danielle Gulden 14:01**

Gosh, this was back in 2013. I lived in Cleveland with my family. And my husband accepted a job in Columbus. So my daughter and I stayed home to finish off the school year to sell our home. And I was very, very involved in both the Crohn's and colitis foundation up in Cleveland as well as the United Ostomy Association. And so I'm not gonna lie, I was a little bit salty about having to move I had the Cleveland Clinic in my backyard. That is where I had my life saving ostomy surgery. That's where all my positions were. And so it was a little bit difficult for me to accept the move, even though I had lived there for six years in between when I went to school.

So I jumped on, on social media and kind of just threw out and a couple of the big IBD support groups that I was in. And I just kind of said, Hey, I'm moving from Cleveland to Columbus. Has anybody there that's in Columbus is, are you involved in Any support groups, I'm really trying to get a hold of this. And Joe jumped in. And he was just like, Hey, I'm Joe, I live in Columbus, I attend ostomy support group, I would, you know, be happy to meet you and go when you and your family arrived. So we just kind of started exchanging some messages, just here and there.

And we ended up meeting in the end of 2014, at the ostomy, the Central Ohio United Ostomy Group, which were actually president and vice president of now. So that's fun, full circle moment. I don't know, it was just kind of a magical thing. You know, everyone, I think, part of, of IBD and ostomy life for us, is really finding your tribe, you know, having those people that you can go to whether they be online or in person.

And so this was a big moment for me to re-find a different tribe and a different city. And it was super important. So we started going to the monthly meetings, and then we started hanging out a little bit afterwards, just, you know, going for a drink right after the ostomy meeting. And it was amazing, just how much that we had in common. And I had friends who had IBD or ostomies, up north, but they weren't really in my age group. They didn't really share my bizarre sense of humor. And so it was an absolutely life changing moment to meet Joe.

And our friendship just kind of fell into place. It was amazing.

**Joe Teeters 16:20**

Yeah, yeah. And for, for me, as Danielle was saying, they're not having someone in the group I had started going to group in 2013, after I was, while I was recovering from my ostomy surgery. But when you go to the group, even being 40, at the time, most of the people in the group were older, and not too many people have had IBD. And so when Danielle showed up, and having someone who was so close in age, so close in health history, it things just really clicked plus our bizarre sense of humor. Yeah, matches perfectly. So...

**Danielle Gulden 16:56**

We like to tell poop jokes.

**Joe Teeters 16:57**

We do.

**Amber Tresca 16:58**

Shocking.

**Danielle Gulden 17:00**

We embrace this lifestyle.

**Amber Tresca 17:02**

So at what point did you decide that you were going to be a dynamic duo and create Double Baggin' It? Whose idea was it? And how'd you get started there?

**Joe Teeters 17:11**

I think it was the gods, actually.

**Danielle Gulden 17:12**

I think the Earth aligned. I do feel that way. And I don't know, we just started really talking to each other and telling our stories, and, and we realized that not so many people around us were doing the same and that that's totally okay. But we were like, wow, we think that we can really use our humor, and tell our bizarre stories and break down some barriers. So we started coming up with some ideas. And of course, it came out of a joke, you know, the name and everything. But it works, it worked.

**Joe Teeters 17:44**

Things really clicked, we went to a national conference, United Ostomy Association Conference in 2015. And that's when things really clicked, we were there with 400 and some other ostomates, and with all different varied health journeys, and seeing different people tell their stories and share their stories and seeing in person, how impactful that was. And we wanted to be a part of that. We wanted to share our voice because there are so many people who, for whatever reason, don't want to, or they can't, or are not able to, they're not comfortable to. So we wanted to jump in.

**Danielle Gulden 18:16**

Yeah, so we were in St. Louis. And like Joe said, we had met 400 some people, which was just so eye opening and so beautiful. And I'm not a very emotional person. But I will say that I went after the first day I went up to my hotel room and I called my husband and I just like couldn't even talk I was just, I had no idea how important that would be for me to meet so many people like myself because I've always been so outgoing with everything. I've been very transparent with my health journey, but just being around so many people and being able to share these stories in this time together was just astounding.

And so you know, we were there for maybe five days I think and we just kept kicking around the idea, we met somebody who we had talked to somebody who inspired Joe for a really long time and he just said to us you know what you guys can't wait around, you need to make this happen and he challenged us, to, start this he's like you know go make your first video ,go open some social media channels do this before you leave, because if you don't, you're just gonna keep pushing off which honestly, is true because we are the both the biggest procrastinators I never thought I could meet somebody on my level of procrastination But Joe has taken that lead.

**Joe Teeters 19:27**

I'm called H2O because I always take the path of least resistance.



**Danielle Gulden 19:32**

But, so that night we we went up to the rooftop of this fancy hotel in St. Louis and made just the most like looking back on it, it's just the funniest little video we were nervous it was shaky. It was a GoPro. It but it was it's beautiful. It's a beautiful thing, our first video just setting the entire stage for what was to come for the next you know 5 to 6 years now but you Yeah, it was amazing. It was so double bagging. It was born on a fancy St. Louis hotel rooftop.

**Amber Tresca 20:05**

How did you come up with the name? Was it something that you workshopped?

**Danielle Gulden 20:09**

I don't know, we were... We were trying to figure out who which one of us said it. My husband claims that he came up with it. No one knows anymore. It's been... You know, I don't know. It just turned into something. We laughed about it. We're like, wow, that could that could give a lot of interesting thoughts. But we, you know, it's stuck with us. It's true. He has a bag, I have a bag. We're all about awareness and advocacy. So it has a good ring to it.

**Joe Teeters 20:33**

Well, and I know my own lack of knowledge at the time, which we've since has been corrected, didn't realize what double bagger actually meant, you know, there were double estimates out there who are double baggers themselves. So we feel a lot of those questions. People think we both are actually double baggers, but it's just we're a double bagger. We because together we're one, a double bagger. So...

**Danielle Gulden 20:56**

we definitely are nearly the same human except that you follow rules. Yeah. Yeah. To clarify, we both have permanent ileostomy Yes. And part of my story at the beginning,

**Amber Tresca 21:09**

I think because I've always known a little bit about who both of you are and your stories. It never occurred to me, but I can see how the double bagging, it might lend itself to someone who does live with for instance, an ileostomy and a urostomy, or something like that.

**Danielle Gulden 21:24**

I have a couple friends who have both so they're both. They call us The Imposters.

**Amber Tresca 21:31**

That's hilarious. Oh gosh, I have this like Capulet/Montague thing now and, like, next, United ostomy Association meeting, you guys should like you know, get a rumble going. You and some of the people that are real, really double bagging it.

**Joe Teeters 21:47**

I could do West Side Story.

**Danielle Gulden 21:48**

I was just gonna say I saw that. He started and you guys can't see it. But he started clicking his fingers. He's some theatricals here.

**Amber Tresca 21:56**

Get ready for it, Yeah. What are some of the events that you guys have done together?

**Danielle Gulden 22:00**

I think our big one was in 2019. Yeah. 2019 are the national UAA which is United Ostomy Association of America. Their national event was in Philadelphia in August of 2019. And we were super honored and thrilled to take the stage on their big entertainment evening.

**Joe Teeters 22:21**

We performed there. And we've had many opportunities to speak with local groups here in Columbus as well as we've worked with ostomy company presented to their employees and shared our stories and that kind of environment. And this year was going to be like a breakout year for us. We had not, not COVID breakout.

**Danielle Gulden 22:43**

Oh, can I get a lecture to get words a little bit better?

**Joe Teeters 22:47**

We had four different keynotes planned for this year. But obviously, life had other plans. The world had other plans.

**Danielle Gulden 22:55**

We have we'll have four keynotes next year and then some so but yeah, we've we've been to various conferences. For ostomies. We've done things with the Crohn's and colitis Foundation, we've been lucky enough to be honored as honored heroes in 2017. So that really started our speaking circuit locally for us with different companies and different hospitals,

**Joe Teeters 23:16**

Oh, and HealtheVoices, we've attended and performed there as well.

**Danielle Gulden 23:21**

Yeah, we've done a lot of really cool things, I think one of my favorite things that we do that a lot Not a lot of people are aware of, and not a lot of people get the chance to do. And I think this is really important, especially in the IBD community, because we don't seem to be looked at in this way. But Joe and I have a good friend from college, who is an occupational therapist and a professor. And she invited us to her college classroom up in northern Ohio, and we had an opportunity to let the OT students learn more about inflammatory bowel disease as well as ostomies. And how they can, you know, help us especially after surgeries, or even in times when we're in a bad flare.

And so it's been very important, I think, to us and to them as well, to have that opportunity to be able to ask any questions. We've actually we've gone a few times now and we kind of take it a step further every time we go. First, we just kind of told our stories and how IBD affects our daily lives.

And then we kind of moved on to hey, these are ostomy bags, Hey, you know what we're gonna have the students wear the ostomy bags, and of course, we filled them with chocolate pudding. Because why wouldn't we? And then the very next time something I had to wear them for the whole two hours. And then we were like, hey, one step up. The very next time we went we have different group of students wear the bags again. And then we had them open them and empty them into the toilet, which was really eye opening for them with the amount of dexterity it takes especially maybe for older patients.

So I think that's been one of our most exciting and important events that we've had the honor of doing.

**Amber Tresca 24:56**

That's fantastic. Whose idea was it? The pudding in the bag?

**Danielle Gulden 24:59**

Probably me. I'm gross.

**Amber Tresca 25:02**

No, but I mean, that's accurate. Because, you know, think about a lot of us live with arthritis and other you know, mobility concerns. And so understanding firsthand how an ostomate, like you said, might need the dexterity to just empty the bag and like, let's be honest, not get it on yourself.

**Danielle Gulden 25:20**

Right? It was funny. Joe took the male student in the male bathroom, I took the female students in and we were, we had a fun time laughing but they're like, how do you do this? our legs are, like, quaking, like, how do you not get this all over you? It's really funny. Funny, but educational.

**Joe Teeters 25:34**

A fun part of that experience as well was the, they took the bags off after they were wearing them. One of the students, one of the students was, I don't know if it was a dare that came up, one of the students was going to eat the pudding out of the bag. And some some were doing it I guess, and using spoons this student took that held the bag up and was trying to like eat it out like a pastry bag or something and couldn't figure it out and asked us like, how do you do this, we're like, we don't know, we never take anything out. We always put stuff into it. We don't know the best way to do it.

**Danielle Gulden 26:02**

We don't do that. But it was funny. Another really cool thing too, which was a first for me, and then I've been doing it ever since is I actually changed my bag in front of the students and I let them help me because my friend who's been doing this forever, she's like, there's countless times that I've had to help a patient change their ostomy bag, you know, during one of our occupational therapy sessions, and it's always, you know, an emergency that that comes up. And so it was really great to be able to do that. It was like a show it was a stoma show and tell, you know, and they're really excited to do it.

**Amber Tresca 26:37**

I've heard from different people who live with a stoma, that sometimes when they see someone out of the GI or colorectal specialty, you know, go to a dermatologist, for instance, they get they get passed around a little bit because they don't maybe see stomas very often. So, you know, that's wonderful that you're serving as guinea pigs for these folks and getting them more comfortable with seeing stomas, understanding what ostomy life is understanding that not everyone who has an ostomy is an elderly person, or has it because of colon cancer that, you know, there's, you know, all different ages and reasons for having a stoma.

**Danielle Gulden 27:14**

Right, and I think the the more comfortable, you know, other health professionals are, the more comfortable the patients are going to be especially those directly out of their surgeries.

**Amber Tresca 27:24**

Absolutely. We've all heard horror stories from other patients about what they hear sometimes from other health care professionals who ostomies are not part of their daily work. So that's fantastic that you do that. Why is it important to you, though, that you do this work, and that you you also do activism as well as your advocacy.

**Joe Teeters 27:43**

For me, it's very important. I spent up until my ostomy surgery, my ostomy journey and my IBD journey. They're obviously very intertwined, I wouldn't have the one without the other. And prior to my ostomy surgery, I wasn't really done involved I not that I was very stoic, but it was just, it was part of my life, I would occasionally go to Crohn's and Colitis Foundation, bowl-a-thons, or what have you. But I never other than that I never really paid attention to it.

It wasn't until my ostomy surgery that I desperately needed the community. And I found the community and I realized how important that community was and how, how important it is for people to know, not just, not just patients, not just patients to come together and learn from each other. But how important it is for non IBD patients, how important it is for the healthcare community, how important it is for employers, how important it is for a government, how important it is for everyone to know what it's like living with IBD.

And, you know, the same token what it's like living with an ostomy. So that, that really drives me in secondarily, part of my experience, the reason I needed that community with my IBD journey. Throughout the years, I've dealt with depression and anxiety to varying degrees wasn't

till my ostomy surgery that I really went into a really deep dark depression. And that's why I was reaching out for the community, the way I was able to come back from that was through the community that was a big part of pulling me back in saving me, if you will, so that that ability to reach out and speak for people who can't speak for themselves, to help people either not get to a dark place, or to come out of dark places and realize that they can live their life to the fullest that, that really drives me.

**Danielle Gulden 29:33**

Very well said, Joe.

**Amber Tresca 29:34**

I know how do you how do you top that, Daniel?

Danielle Gulden 29:36

Yeah, that is a good point. He's, you know, he's a 601er like on The Price Is Right, we always say that it's always got to be. And that's what I call him all the time.

But so for me, I think it's twofold. Everything that Joe said of course, but I also think we kind of take it down a level we really put things out there in two different ways. We do things in a silly ways. With our humor, I'm just to break down some barriers as well as to educate people. We do a lot of times when you know, when it's a nonpandemic year, we go places and we put ostomy bags on statues, you know, we've gone to the zoo, we've gone to holiday events, we've gone to various statues in our city, and just placing an ostomy bag on there taking a picture posting on our social media, and just really normalizing ostomies, normalizing IBD you know, everyone poops, we just poop through a hole in our stomach instead of our butts, you know. And we're not joking, we say to best friends without buttoholes.

You know, we we put it out there for a reason. And so we do these things, we call them ostomy bombs, and we're just placing them out there. And a lot of times people in the community will come up to us and be like, you know, what is that, or we'll have somebody who knows what it is. And they're like, Wow, that's really great that you guys are doing this. And you know, we really appreciate them.

On the flip side, we also take our activism to our local government, as well as to Washington DC, we are always really excited and happy to participate in the IBD Day on the Hill through the Crohn's and Colitis Foundation. And, you know, I really enjoyed that time. Because being able to speak to the people making the decisions in our country is so empowering and so important. And, you know, I'm always the one in the office that says the uncomfortable things, and I'm happy to do that IBD, ostomies, they're not pretty, you know, and...

**Joe Teeters 31:30**

I like mine.

**Danielle Gulden 31:31**

My stoma is pretty, I'll give you that. But you know, just the life and when so many people are embarrassed by it and are so sick to even be able to do this. So we're so happy that we can take our voices to Capitol Hill, and have these very important conversations. And you know, I'll be the first one to sit in that office and be like, we need to get some things changed here. Because I've lost my colon, I will actually say I've lost my buttohole to IBD.

And I want, you know, I want research, I want things in place to help other people not have to go through what we have. Not that ostomies are a bad thing, their life saving. I love mine, it was one of the best decisions I've ever made in my life. But to be able to, you know, save somebody else, have them not have to go through it. I think it's so important. So I'm happy to lend my voice and tell my stories of pooping in places I shouldn't be pooping and you know, running down that college hallway to find a bathroom and sometimes not making it. I'm happy to tell those stories so that we can get our voices out there and make it as important as it is.

**Joe Teeters 32:36**

Yeah, just adding on or re-emphasizing that we we share our stories and experience with the Congress and people making decisions as a cautionary tale. We're happy with the life that we're living. We're living our life to the fullest. But if we can have a better outcome for the 17 year olds today as then than what 17 year old us had, then we want to do that.

**Danielle Gulden 33:00**

And then our jobs here are done. Yes, we will continue.

**Amber Tresca 33:03**

That's accurate. And I feel exactly the same way.

[MUSIC: ABOUT IBD EMOTIONAL PIANO]

**Amber Tresca**

Is IBD funny?

**Danielle Gulden 33:20**

I mean, I think the diseases are not funny. But you know, there's a silver lining in things And much like toddlers can show us poop is funny. Farts are funny, you know, and I think humor really, we really believe that humor helps, like I said before, break down those barriers and open conversations.

**Joe Teeters 33:39**

Yeah. A lot of the times I mean, poop poop is funny, farts are funny. But a lot of the times when you're dealing with the things that we all deal with, with IBD it's it's either making a choice of, you know, can you laugh? Are you going to laugh? Are you going to cry and sometimes both, most, a lot of the times both, but it's trying, you have to laugh as a coping, survival, mechanism.

**Danielle Gulden 34:04**

Because there's gonna be times that you will inevitably poop your pants or poop your shirt depending on where your pooper is.

**Joe Teeters 34:09**

I might be doing it right now.

**Danielle Gulden 34:11**

I mean,

**Amber Tresca 34:12**

Are you pooping right now talking to me?

**Danielle Gulden 34:16**

Thinking so therefore, yeah, you can't hear and that's fine. But yeah, we're just...

**Amber Tresca 34:20**

Sitting there, pooping away.

**Danielle Gulden 34:21**

I earned that, I earned that poop at the dining room table, you know? Yeah. No, I do think that it's okay to laugh about it. And some of the things that we joke about and laugh about now, we're certainly not funny when it happened to me.

**Joe Teeters 34:33**

Absolutely. And it's a fine line. Like we were finding the humor. We joke, just the two of us together. We're laughing and joking all the time. But you definitely have to be and we hope that we are that we're recognize that not everybody is in that same place of finding the humor or finding humor, being able to laugh and we totally recognize that we try to be we try to be graceful, I guess about that or honor, honor that. I guess read the room. so to speak, right? And make sure that we're not being inappropriate with someone who's not to the point we are yet.

**Amber Tresca 35:04**

Do you have a favorite story about your ostomy life?

**Danielle Gulden 35:08**

There's so many. One of my favorites early on, involves my daughter. So she was three and a half, when I had my ostomy surgery, she'd only ever known me as really sick. I never could take her to the park when I was really ill, unless that Park had a really good bathroom. I actually had, you know, I had a toilet installed in my car, to be able to go places and to do things. And that's sad, but it worked. And I'm happy I did it. But so when I had my surgery, all Lauren knew is that I was healthier. She knew that I could do more things. And she wanted to tell the entire world.

So imagine this three and a half year old, little adorable human sharing this with all of the world. So two things happen. One, her babysitter, they had, it was an at home babysitter. And

so there was a couple new babies that came in while I was in surgery. So my first first availability to pick her up and be able to actually hold her was eight weeks after my surgery. I went to pick her up at the side door. And one of the new moms was there. And she's like, Oh, I met your daughter. And you know, oh, congratulations. And I was like, oh, wow, thanks. Like that's really folding and sushi. So my stoma is named Stella more named it. And she's like, you know, I'm really excited to meet Stella.

Wow, I didn't know what to do with that yet. And I was like, um, and then it like, it took me a little bit of time. And then I was like, Oh, my gosh, Stella's my small intestine that sticks out of my stomach because I have ulcerative colitis. But it was the funniest thing. And so Lauren had apparently been telling everyone for eight weeks. And so all the new moms thought that I had a new baby named Stella, and they didn't realize that although new babies poop all the time. It was just my stoma, it was really funny.

And then another quick one. I had taken Lauren to the grocery store, I despise shopping, but I really enjoy grocery shopping. And so it was super exciting to be able to lift her again and to be able to do things on my own. And so we were checking out of the line. And she was in one of those little grocery carts. It's like a truck. And so she was facing the person behind us. And she just the lady just started talking to her and she's like, Oh, hi. And she's like, my name is Lauren and my mom has a bag of poop on her belly. walling it and the cute is like Imagine Big blonde pigtails and giant blue eyes just the entire group of humans within 20 feet of her that her mother is pooping right now.

It was- a but she was she was my like she was I think honestly, she started me down the advocacy road because she was just like taking that from a three year olds perspective. My mom is healthy again. And and that was, it was you know, heartbreaking that she realized that I was sick for so long. But it was really a kind of a beautiful moment. So those are my favorites, the ones that involve her. I think she really started me on the awareness and advocacy journey.

**Joe Teeters 37:48**

Those are my favorites too.

**Amber Tresca 37:51**

Do you have one Joe?

**Joe Teeters 37:52**

I do. And mine is mine is my story of acceptance and growth. And I had my surgery at the end of 2012 and 2013 was a what I call a last year because of the year I spent in recovery and trying to get back back into my normal my quote unquote normal life and social life and such and I do big part of my life is I do improvisational comedy and theater and such and at the time I had my ostomy surgery, I didn't think I'd ever be able to be on stage again.

But at the end of 2013, I was able to get back on stage and get back into improv, and in 2014, in May of 2014, I ventured out to go to an improv camp and improv retreat for adults. And I was



very nervous first time traveling with my ostomy, and I'm nervous about being in this camp with an ostomy, I was still afraid of people knowing that I had an ostomy, seeing my ostomy, hearing my ostomy. So at the camp, I pretty much kept myself I got my own little cabin. Everybody else was staying in a big ol' like kids campground cabin. By my own little place. I stayed a very reserved stayed to myself. You know, there were parties each night at the gazebo, I just did my classes went back to my cabin.

Well flash forward to I went to the same retreat in 2015, in 2015. And coincidentally or not, after I met Danielle, by 2015, I was as we like to say all the time, I was definitely rocking out with my bag out, because I was, I was imbibing in adult beverages. I was partying at the gazebo each night. And on the last night there is I maybe overindulged in some substances, and I had a blackout moment of which kids at home I don't recommend this. Do not, Do not do this. Do not try this at home at a moment where I lost a period of time that night, like four to five hours of time that I don't remember. Yes, I know. It's, it's crazy. It's crazy.

But one of the last things I remember before that moment, it was I'm standing on the landing of this cabin with I don't know how many people around me four or five other people. And I remember myself saying "It's true, I don't have a butthole!" And then flash forward through that my when my memories start coming back is I'm standing on that same landing and people are coming, people are coming out with their bathing suits and going to go swimming in the lake. And the rule was you couldn't swim in the lake at nighttime, and I was like, we can't go swimming, it's nighttime and they go, No, and I turn around and the sun is coming up, it's right over here.

And so I find myself walking down and stripping down to my underwear and my ostomy bag all out and jumping in the lake with this with four other people. And that's when I came to. So I definitely had a lot of growth. From my experience in 2014-2015. I was definitely very, very comfortable with people knowing that I had an ostomy

**Danielle Gulden 40:42**

You were raising a lot of awareness.

**Joe Teeters 40:44**

I was.

**Danielle Gulden 40:44**

Raising a lot of awareness.

**Amber Tresca 40:47**

That's definitely a 180.

**Danielle Gulden 40:48**

You always play the innocent one, but... yeah.

**Amber Tresca 40:54**

Is there anything that you want to add or anything else that we should cover?

**Joe Teeters 40:56**

I think just the only thing to add just from the work that we do, it's something that we like to impart it to all people with IBD or ostomies. And we say it in both patient communities is you know, we realize we're out there, we're out there so much we we always say rock out with your bag out. And we literally rock out with our bag and stuff. But we know that everybody is uncomfortable with that we know that everybody isn't comfortable being open with their IBD journey or open with their ostomy. But we like to say you know, it's okay to hide your IBD it's okay to hide your ostomy Yeah, but

**Danielle Gulden 41:28**

don't let your IBD or your ostomy bag hide you. And that's our wisdom.

**Amber Tresca 41:34**

Joe. Danielle, thank you so much for being on my show.

**Danielle Gulden 41:37**

Thank you,

**Joe Teeters 41:37**

Thank you very much

**Danielle Gulden 41:39**

For everything you do for our community.

**Amber Tresca**

Thanks, guys.

**Amber Tresca 41:48**

Hey, super listener! Special thanks to Danielle and Joe for taking the time to tell me their stories and for all they do to support and uplift the IBD community through their humor and their work.

You can follow Double Baggin' It on social media. On Instagram, Twitter, and Facebook as @doublebagginit, and that's baggin without the final "g."

As Joe and Danielle told their stories, I was reminded how many of us who live with IBD have changed our life trajectory because of our disease. Because people are often diagnosed young, career choices are important, and for Joe, Danielle, and myself, we needed to pivot and find new directions. Another important part of Joe's story was that he needed to work full-time in order to have health insurance. Under the affordable care act, kids can stay on their parent's insurance until they are 26 years old. Had the ACA been in place at the time of Joe's diagnosis,

he may have been able to continue with school. And this is one of the reasons why it is important to protect the ACA and also work towards improving it. I will put more information about this and the other topics we discussed in the show notes and on my Episode 86 page on AboutIBD.com.

Thanks for listening, and remember, until next time, I want you to know more about IBD.

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**

I wish I could hug you, next time I see you, I will hug you for a very long time.

**Joe Teeters 43:31**

Yeah,

**Amber Tresca 43:32**

I wanna be the meat. Can I be the meat in the sandwich?

**Danielle Gulden 43:35**

In the DBI sandwich? Absolutely.

**Joe Teeters 43:37**

100%

**Joe Teeters 43:40**

It may be warm depending on if it's after....

**Danielle Gulden 43:42**

Oh my god Joe, don't be ostomy gross. See what I mean?

**Amber Tresca 43:49**

I'm there for it. All the warmth