

About IBD Podcast Episode 108

Colitis Conversations: The Impact of Ulcerative Colitis

Inflammatory bowel disease (IBD) affects our quality of life. What that means, however, is going to be different for each person. It may depend on many factors including disease severity, access to care, and support structure.

The symptoms of ulcerative colitis such as diarrhea can prevent people from taking part in activities that aren't near a bathroom. Bleeding can cause anemia, leaving people feeling tired and unable to go about regular activities. Not to mention the effects on mental health, relationships, and finances.

Danielle Gulden, ulcerative patient, ileostomate, and co-founder of Double Baggin' It and Dr Nana Bernasko, IBD Nurse Practitioner and Assistant Professor of Medicine in the Division of Gastroenterology and Hepatology at Penn State Health, discuss how to manage the effects of IBD on everyday life.

Concepts discussed on this episode include:

- [Rectal Bleeding and Inflammatory Bowel Disease](#)
- [The Impact of UC: Quality of Life](#)
- [The Impact of UC: Complications](#)
- [Types of Ulcerative Colitis \(UC\)](#)
- [What Inflammatory Bowel Disease Pain Feels Like](#)
- [Can a Gastropsychologist Help With Inflammatory Bowel Disease?](#)

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Find Danielle Gulden of Double Baggin' It on [Instagram](#), [Twitter](#), and [Facebook](#), and [Tik Tok](#).

Find Amber J Tresca at [AboutIBD.com](#), [Verywell](#), [Facebook](#), [Twitter](#), [Pinterest](#), and [Instagram](#).

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[MUSIC: IBD Dance Party]

Amber Tresca (00:05):

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 108. This podcast is part of the American Gastroenterological Association Colitis Conversations Program.

Amber Tresca (00:24):

Living with an inflammatory bowel disease has a significant effect on quality of life. Ulcerative colitis tends to cause diarrhea and bleeding. The diarrhea can lead to all kinds of problems with quality of life, including not being able to take part in activities that aren't near a bathroom.

Amber Tresca (00:40):

The bleeding can cause anemia, leaving people feeling tired and unable to go about their daily life. Of course, there are also plenty more, including the effects on relationships and mental health.

Amber Tresca (00:51):

To dig into how the symptoms of ulcerative colitis affect quality of life, I talked to Danielle Gulden, ulcerative colitis patient and ileostomy, and Dr Nana Bernasko, an IBD nurse practitioner and an assistant professor of medicine in the Division of Gastroenterology and Hepatology at Penn State Health.

Amber Tresca (01:09):

Dr Bernasko describes how she approaches patient care to help address quality of life issues that might otherwise get missed. And Danielle tells us how her disease affected her life, including a major change that she made to her car.

Amber Tresca (01:24):

Our topic today is quality of life associated with ulcerative colitis, including complications and an understanding of the severity of the disease. My guests are Danielle Gulden and Dr Bernasko. Dr Bernasko, thank you so much for coming on About IBD.

Dr Nana Bernasko (01:42):

Thank you so much for having me here today.

Amber Tresca (01:45):

Danielle, this is your second appearance on About IBD. So, thank you so much for coming back.

Danielle Gulden (01:50):

I'm super honored.

Amber Tresca (01:52):

So, this is a really broad topic. And I think that every person with ulcerative colitis would define it differently. But Danielle, I want to start with you. What are some of the important things that come to mind when you think about quality of life as it relates to having IBD?

Danielle Gulden (02:08):

I think the most important thing for me is just how much it affects every activity of daily living. From the moment I open my eyes in the morning to the moment I'm exhausted and go to bed, it's unfortunately a constant presence in my life.

Danielle Gulden (02:24):

And the most impactful things I feel that for me is just about parenting. My daughter is now 17, but I've been ill since I was 17, as well. And so, she's only ever known me as having this disease. And I think that's the thing that I'm just most aware of is how it affects parenting, how I can keep my household going while working and doing all the things in between. So, I'm very aware of that, and it's a super, super important thing and a super important topic.

Amber Tresca (03:00):

Yeah. And it's so funny how you say. You don't just say, "Oh, I go to bed at night." You're like, "I'm exhausted. I go to bed." That's an important point is the complete exhaustion that you sometimes live through during the day.

Danielle Gulden (03:12):

Exhaustion, but then you can't sleep. So, that's a fun twist.

Amber Tresca (03:17):

Yeah. And then, I think a whole other topic and I'm going through this myself is being perimenopausal and how that impacts your sleep and impacts your IBD and everything. Maybe you and I will have to jump on this another day.

Danielle Gulden (03:31):

Absolutely.

Amber Tresca (03:33):

So, Dr Bernasko, I think IBD patients are pretty stoic, if I do say so myself. What are some things that maybe your patients aren't telling you about, but that you wish that they would so that you could help them better take care of themselves?

Dr Nana Bernasko (03:47):

Absolutely. So, certain things like how they're dealing with their disease mentally is an important factor for me, as well. I would like to know what their day-to-day life is like having this disease. Are they able to function? Are they able to go to class? Are they able to take care of their kids? Just how does your life function with this disease on board? And also, sexuality, that's definitely an important part that I like to pick, talk to patients about if they don't bring that up.

Amber Tresca (04:22):

Yeah, that's huge. And I think it often doesn't get brought up, of course. I think also patients might not realize that their team can help them with things beyond prescribing medication. So, Dr Bernasko, do you have an example or more than one example of a situation where you helped a patient that went beyond just prescribing medication or helping them with those treatments?

Dr Nana Bernasko (04:47):

Yeah, I actually have quite a few of those examples. The one thing that I'm lucky to have in our IBD center here is that we do have a psychiatrist on board and also a nutritionist. And it's not something that's heavily advertised. And so, when I have patients in my clinic, I will pry a little bit and say, "How are you doing with your nutrition or how you mentally coping with all of this?" And then, I offer those services if they feel like they need them.

Dr Nana Bernasko (05:17):

Other things that we do here as well is that we do have an excellent support team. We have support groups, and we meet every quarter. And these are IBD patients that come together and talk openly about the disease. And sometimes, we do have special guest speakers as well. And then, they have programs like yoga.

Dr Nana Bernasko (05:39):

And then, we'll have a special feature where we'll have somebody come and do meditation with them. And so, those little things that we can offer them outside of just prescribing medications, we definitely let them know when they're here.

Amber Tresca (05:54):

That's fantastic. Wow, that's really taking care of the whole person.

Dr Nana Bernasko (05:58):

Absolutely.

Amber Tresca (05:59):

That's amazing. I love that. Danielle, how about you? Are there some things that your healthcare team has brought up to you or offer to you that has helped you with your quality of life outside of just prescribing medications?

Danielle Gulden (06:10):

I'm going to go with empathy. I have the most empathetic team that I'm just so thankful for, honestly. They've been amazing. Actually, my primary care physician does such a good job of... she's the cog in the wheel. So, she is my communication specialist. And I cannot be more thankful for her.

Danielle Gulden (06:32):

She keeps me connected with all of my specialists, so Michael, I have two colorectal surgeons, because everyone should have two, right, a GI pelvic floor therapist and some other of my

specialists that unfortunately my IBD has affected other... I'm very medically complex. So, it's affected me in other ways.

Danielle Gulden (06:52):

And I'm so very thankful for all of their communication. To me, that's the most important thing. So, I don't have to repeat myself. They already know everything when I see each of them individually. And that I'm very grateful for.

Amber Tresca (07:05):

Yeah, the repeating yourself. I mean, there's lots of cases where it happens and you understand it before you're having surgery, and you have to repeat yourself to everyone that walks in the room.

Amber Tresca (07:16):

But it is really great when you can come into one of your doctor's appointments and they already know what went on at the last appointment you had last week or the week before or whatever, and you don't have to repeat yourself there. So, that's a really great point. It's something that I think can really help with your quality of life as well and lower your stress levels.

Danielle Gulden (07:37):

Yes, it's so refreshing to not have to keep repeating and just being... I feel like I'm so heard. I don't have to explain myself to each person. Even when I have a new person come in, I feel like they're already very well versed on me and that's so important.

[MUSIC: About IBD Piano]

Amber Tresca (08:05):

Talking about affecting the whole person, there are some complications that come along with ulcerative colitis. And I think that especially newly diagnosed patients might not know what those complications are. I think there's reasons for that. One of them may be being that practitioners might not want to overload people with all of the things that could happen. Dr Bernasko, what are some of the complications that you might see in your ulcerative colitis patients?

Dr Nana Bernasko (08:30):

They're actually quite a number that we can talk about today, including weight loss. Weight loss is one of the few things that will show up earlier on in the disease. And most of the times, people avoid eating because when they eat, they have to move their bowels. And so, for them, in order to make it through their days, they decide not to eat. And so then, they have this drastic weight loss.

Dr Nana Bernasko (08:53):

The other thing is that with ulcerative colitis, there's definitely some rectal bleeding involved. And so, these patients will show up very anemic. And sometimes, it happens over time. And so, they don't realize how anemic they are until we look at their blood work and they were like, "Oh my God. How have you been walking every day and not know that your hemoglobin was this little? How have you been functioning with such low levels?" That's another one.

Dr Nana Bernasko (09:21):

And then also, obviously, the diarrhea, 15, 20 bowel movements a day. Tenesmus is when you have the feeling like you got to go, you got to go, but then there's nothing that's coming out. And then also, incontinence. When you don't make it to the bathroom in time, you may have periods of accidents. And so, some of those things are very important to talk about as well.

Dr Nana Bernasko (09:43):

And then, things that you may not actually even notice is happening with IBD, a lot of times, patients will end up being on steroids multiple times. And that can actually make their vitamin D deficient and then cause them to have thinning bones which would be like osteopenia or osteoporosis. And so, just outside of the gut, there's so many other things that can take place as well just that you may not be aware of, as well.

Amber Tresca (10:11):

Yeah, and something that you're referring to and a word that I like to use to describe it is insidious. I like to call ulcerative colitis insidious because these things like anemia sneak up on you. We might normalize a lot of things with ulcerative colitis. So, I'm wondering Dr Bernasko, what do you tell your patients are the things that if they're seeing this in themselves that they need to call you right away and they need to be seen?

Dr Nana Bernasko (10:36):

Absolutely. Diarrhea that does not get better over time, and then also profuse bleeding, rectal bleeding. Those are alarming signs that you need to pick up the phone and call us immediately when those things can happen.

Dr Nana Bernasko (10:50):

And then also, severe abdominal pain. Some patients do have a level of abdominal pain that they're used to. If it seems like it's completely out of whack, out of hand, this is new, I've never experienced this before, definitely a red flag to call us immediately.

Amber Tresca (11:07):

It's such a shame to talk about. There's a certain amount of pain that some people get used to it. That's the way that it happens. And unfortunately, normalizing it, we need to bring these things up when we go into see our providers that we are experiencing pain.

Amber Tresca (11:20):

So, Danielle, obviously your disease became severe at points in your life. Did you recognize when that was happening? Or was there someone around you who said, "Hey, this is not right anymore, and we need to get this dealt with?"

Danielle Gulden (11:34):

Yeah, I have an interesting story about that. So, I was misdiagnosed with having gluten issues, gluten intolerances for six years. And yes, so that was a joy. That was a gem to be diagnosed in college and having to find things when not all the Whole Foods types of places were around yet.

Amber Tresca (11:53):

No.

Danielle Gulden (11:53):

So, for me, I was immediately diagnosed after a colonoscopy with severe ulcerative colitis. There was no ups and downs. It was severe my entire journey, unfortunately. But I will say, Dr Bernasko, you described to me to a tee with the weight loss. And my hemoglobin was just bottomed out. I think it took such a long time to get there that I just became very used to it.

Danielle Gulden (12:24):

And so, the same thing, when I had my blood work ran, it was like, "How are you driving? How are you going to school? How are you working?" And I'm like, "I don't know. This is all I've ever known. What? This is news to me. You mean, most people don't feel like this?"

Danielle Gulden (12:41):

But for me, it's like I knew I was losing weight. Because again, I also did not want to eat because I wanted to get through an entire shift at work without spending 20 minutes in the bathroom with 10-minute increments in between, which is so... I mean that was awful.

Danielle Gulden (12:58):

But for me, it was when I saw some photos. And I put up some pictures of my now husband, but my boyfriend at the time, and I had them all up in queue and everyone's like, "Oh, why you look so... oh, you lost a lot of weight." And I'm like, "This is not a good way for someone to be like, 'Oh, you've lost a lot of weight.'"

Danielle Gulden (13:15):

And so then, I started hating those photos because I was reminded that it was just a terrible cycle that I was living through. I would go on steroids, and I would gain some weight. And then, I would be off the steroids for a little bit, right? Never off, but they took me down. And then, I would lose a lot of weight. And so, it was the up, down, up, down.

Danielle Gulden (13:35):

And so, I think I noticed it most because again, this is your daily life. So, I didn't notice it until I saw photos, until people were commenting on those photos. And it was just huge red flags like,

"Okay, this is not normal. And maybe I need to get in to be seen a little bit more." Because I was just used to it. It's unfortunate, you just get used to it.

Amber Tresca (13:57):

You do. And I know that I felt at times like, "Well, this is just how it is. And there's no way out of it.", which is we don't want people to feel like that. We don't want people to go through that because there are ways out of it.

Amber Tresca (14:09):

And the experience of losing a lot of weight, I'll never forget the times in my life where people looked at me and said something like, "Oh, you're so skinny." But it was like, "No. I was emaciated." Do you know what I mean? It was extremely unhealthy and not something that you would want people to envy.

Amber Tresca (14:30):

But they didn't understand what was going on because IBD is an invisible disease, except for the amount of times that you're running to the bathroom while you're at work.

Danielle Gulden (14:38):

Right. That could have been it. It could have just been my marathon sprints. It wasn't that I was eating. It was because I was exercising on my marathon runs to the bathroom 25 times a day. So, it's a new Olympic sport. I would have the gold. I would take home the world's championship with my other fellow IBDers.

Amber Tresca (14:56):

And literally running and not only that, but squeezing your glutes.

Danielle Gulden (15:01):

It's an entirely different exercise program. Bonds of steel.

Amber Tresca (15:08):

Bonds of steel. Amazing. May wish to market that. Let's talk afterwards, Danielle.

Danielle Gulden (15:15):

Sounds good.

Amber Tresca (15:16):

Yeah. It's not a surprise that people with IBD use complementary therapies. They just do. But I think that is sometimes largely in relation to their quality of life. So, I'm wondering, Dr Bernasko, you've already talked about some of the things that your clinic offers. What are these tools that you found that are more helpful for your patients as they're dealing with stress and anxiety in coping with their ulcerative colitis?

Dr Nana Bernasko (15:49):

So, for me personally, when I meet a patient, we talk about creating a safe space within our clinic, right? I make it known that you can tell me anything you want to. I always say, "I cannot help you if I don't know." And so, creating that safe space for my patient is key because I want them to be open enough to communicate with me when things don't feel right or sound right.

Dr Nana Bernasko (16:19):

And even just talking to them I think is a good way of decreasing their level of stress and anxiety. I always tell them, "This is a non-judgement zone. I'm not going to judge you for anything you tell me. So, be open as much as you can with me." That's number one.

Dr Nana Bernasko (16:35):

And so, in creating that open relationship, I find that patients do talk to me a lot about everything. Sometimes things that I don't want to know, but that's okay. That is okay. It's fine. I've talked about mother-in-laws and husbands, the whole thing. It becomes a full therapy session, which is fine. I just want you to unload on me because...

Dr Nana Bernasko (16:59):

And just having somebody listen to you can just in itself validate how you're feeling. And I think that patients do like that that they feel somebody is actually hearing them, and they're not crazy. I'm going to say that out loud. Yes. So, that's one.

Dr Nana Bernasko (17:15):

The other thing that I really try to do for them or I tell them is that, "Make time for yourself, even if it's five minutes a day. Just focus on you for a minute. And just get back to Zen with yourself. You need that space for you." Because there are people like Danielle who have children who have to go to school.

Dr Nana Bernasko (17:36):

And everything is moving at a really fast pace. And sometimes, you forget about you. And so, recentering and focusing on you for, again, even if it's a few minutes of the day is another key thing that I try to preach.

Dr Nana Bernasko (17:50):

And then, support groups, can't say enough about those. I mean, just having somebody to talk to you outside of me, whether it's a friend or a companion, or even just going online and talking to people who may have some of the same experiences that you're dealing with, those are all important ways of managing this. And then like I said before, when it comes to more professional stuff, we do have a psychiatrist on board.

Dr Nana Bernasko (18:18):

And one thing that I do want to throw out there is that sometimes you can actually work through your insurance companies. They do offer some of these programs. You just have to look for them and ask, "Is there a therapist that I can speak to? Or is there a psychiatrist that I can make an appointment with?"

Dr Nana Bernasko (18:35):

And even within your jobs, there are employee services that you can access. And so, I try to push patients that way to utilize things that may be available to them that they're not aware of.

Dr Nana Bernasko (18:46):

And just to get back to Zen, I think the mind-gut axis is so important. You come into me as a person, not just as a gut that walks through my door. And so, it's so important that we have that whole holistic approach when we're trying to talk about healing and getting back into remission.

Amber Tresca (19:19):

Danielle, we all experience low times with our disease and you work as an activist. You have your partner Joe Teeters, and you guys have formed Double Baggin' It. And you have a very hopeful and positive presence on what you do on social media and the different events that you do around the country. And maybe not so much during COVID, but hopefully you all can get back to that.

Amber Tresca (19:45):

But I'm sure you've experienced low times. Would you mind describing a time that you've had more difficulty with your quality of life and then how you dealt with that and got out of it?

Danielle Gulden (19:56):

Absolutely. So, one of my favorite things to do in life is to travel and to see family and friends. And I think that I was okay coping with my ulcerative colitis diagnosis up until I realized that traveling during the holiday season or during the winter season in Ohio, down State Route 71, is never a good time when you have raging diarrhea.

Danielle Gulden (20:24):

So, putting that out there, spinning some truths, let's talk about it. Poop fountains, okay. So, for me, that was one of the biggest challenges because being in a car with someone which sounds so weird, right? When you have IBD, you have zero control or very little control.

Danielle Gulden (20:43):

And so, for me, it was either I would drive myself places or my husband, maybe my parents. I would never go in another car with anyone else. I would drive by myself. I would run to separate car, whatever it took just for peace of mind.

Danielle Gulden (20:56):

And when I started getting extremely ill, and none of my meds were unfortunately working as well as they should be, or at all, I decided that I had to take matters into my own hands. And so, Amber already knows, I actually had a toilet installed in my vehicle. And that was one... I know, that's crazy. That's true.

Danielle Gulden (21:15):

Bought a car, took out a seat, put a very fancy camping toilet in there. But it gave me such a peace of mind. And it was not very used very frequently, but when I had to, I had to. And it was good to not have to hold that in or be terrified and white-knuckling it down a major highway. And so, for me, that was a huge, huge turning stone or turning point.

Danielle Gulden (21:40):

I had to take as much control as I could. And so, for me, that was huge because traveling and seeing people and experiencing life is the most important thing. I didn't want to miss out. I missed out on so many events and so many milestones in my family that I was the only one that wasn't there.

Danielle Gulden (21:55):

And as much as people try to understand, it's still hard to be the person that always has to cancel plans. And so, I think that was such a monumental moment when I realized, "I can be creative and do something about this because there's not many things that I can control." So, I did what I could, and hence, the car toilet.

Amber Tresca (22:14):

Yeah, the car toilet.

Danielle Gulden (22:17):

The poop mobile as it's very affectionately called. The poop mobile.

Amber Tresca (22:20):

So, do you think that you actually had to stop to use the bathroom less often because you had that available to you?

Danielle Gulden (22:28):

I think so. Even my husband was like, "Wow, this is amazing." Because I would count the miles in between. I know every route of any place I've ever been. I knew where the good bathrooms were. Sometimes, you want quality over quantity. And sometimes, you want quantity over quality. And sometimes, it's just the three. Whatever that may be, I definitely...

Danielle Gulden (22:50):

Just having the nerves of going, passing one rest stop is like, "Oh, my gosh. There's not another one for 45 miles." That stress, it was like a snowball going down a mountain, right? And then oftentimes, we'd pull off on the side of the road. And once I got to that safe spot, I didn't have to go. It was fine.

Danielle Gulden (23:12):

But having that cute little toilet with the little curtains and a little magazine rack, I'm not going to lie, it's good times. Imagine that, everyone. Put it in because that's what happened. But it

was a peace of mind. And that peace of mind helps calm my nerves. And calming my nerves helped me not have as many bathroom stops. It was good.

Amber Tresca (23:31):

I understand that, yeah. Driving in the car was probably one of the worst. That and waiting to board a plane I think were the two worst times. By the way, Danielle, what year was this that you installed that toilet? Do you remember?

Danielle Gulden (23:52):

Let me think back. This had to have been around 2001. Because I had to think, my daughter was born in 2004. And she was born into the life of thinking that every car had a toilet in it. No jokes, the greatest thing. Here's a fun story. She was really confused. Then when she'd get in my parents' car and she's like, "Where's the potty?" And my parents were like, "No." She thought that they were just not up to speed. "What's wrong with you?"

Danielle Gulden (24:20):

And then, we had a ceremonious thing to get rid of it after my ostomy surgery. And she was also very confused and sad. I think she felt it was like... she's an only child. Perhaps, those are like...that's her pal in the backseat.

Dr Nana Bernasko (24:33):

It's interesting because, Danielle, your story, and Amber, your stories are pretty much similar. This is what I hear from my patients all the time. It's like, "I know every bathroom on my way to your office." And we try to change that narrative over time when we get to work together.

Danielle Gulden (24:53):

That's a beautiful thing.

[MUSIC: About IBD Transition]

Amber Tresca:

The three of us obviously sitting here, we don't have any problem talking about our bowels. But it's really difficult. It's not easy. And it's not easy to go into your healthcare provider's office, especially the first time you have to do it and talk about what's going on, and have somebody asked you, "How many times you go to the bathroom a day? And what does it look like? And what is the consistency?", and things like that.

Amber Tresca (25:26):

But then on top of that, we have topics like sexual and mental health, that patients might really have even more trouble discussing with their health care providers. So, we have to find ways to talk about these things. So, I'm wondering, Dr Bernasko, do you have ways that you help your patients? You create a safe space, but you have ways that you help your patients to overcome these barriers so that they do tell you about what's going on with some of these trickier topics?

Dr Nana Bernasko (25:57):

Yes, actually. So, the other thing that I do is a pregnancy and IBD clinic. And so, in order to start having that conversation from basics, what I ended up doing was putting up fliers in my waiting room and also in my clinic space. And so, while patients were waiting to be roomed or waiting for me to come in, they would see these posters in the room.

Dr Nana Bernasko (26:24):

And that in itself would start that conversation about, "Hey, I'm thinking of having a family soon. And what do you think we need to do with IBD?" Because it basically says, "If you're planning on starting your family or contain your family, bring it up to your provider."

Dr Nana Bernasko (26:40):

And so, I put that in there and get people to start talking about that because it's one thing that sometimes people don't think that we would be interested in. But like I said, for you to have a healthy pregnancy, it's important that your IBD is in remission. So, sometimes patients forget that we're part of that solution as well. So, that was the first thing I did was to just put that out there to start that conversation.

Dr Nana Bernasko (27:05):

And then again, back to the mental part of it, I'm like, "How are you coping with your disease? Is there anything else that I need to know? How's your partner doing? How is your relationship going?" I get all in there. "I want to know who you're dating. All that fun stuff, let's talk about it."

Dr Nana Bernasko (27:22):

And then, once again, once you get used to me and being all nosy and all up in your life, there are things that sometimes I don't even ask you about and you just start telling me about it. And again, it's all about creating that safe space and getting people to open up a little bit.

Dr Nana Bernasko (27:39):

I try not to be so up there. I want you to think that you're coming to see somebody who's here on your team to help you out, versus, "Oh, I'm the doctor. You can't tell me anything." scenario. And so, people think I'm crazy. I laugh so much. I give hugs. I celebrate when people get in remission. And it's a journey for both of us. Because if I get in remission, you're not calling me as much and I know your life is good.

Dr Nana Bernasko (28:07):

So, just again opening that safe space and having that conversation from the get go I think is one of the things that I've been successful in doing with my patients. They like to talk. I like to listen. Let's get it together.

Danielle Gulden (28:23):

I love that.

Amber Tresca (28:24):

I love that. And it's really innovative too, just something as simple as putting up a flyer. It's really interesting. I love that idea. That's really innovative approach that I haven't heard before. So, that's fantastic.

Danielle Gulden (28:35):

I feel the same way. I think like I'm sitting in the waiting room, and I used to have a notepad back in the pioneer days. And now, I have my phone and I'm writing questions. But it's like, if I see that, I'm like, "Oh, I'm going to add that to my little list of questions. That's beautiful. It's wonderful."

Danielle Gulden (28:49):

Because we're usually so in the mode of just, "We got to get in there. We got to make sure all of our questions were met." You think you have to be quick, so you get it all in. But it's like you forget all the really important things that are part of your daily lives because you're just so focused on the basics of IBD that you forget that it affects every single thing around you.

Amber Tresca (29:11):

Yeah. And bringing up those difficult topics, I remember the times when I had to do it. And that for instance, you're recovering from surgery, and nobody told me. It's funny because when I left the hospital after having a baby, I was given very specific instructions on everything that you could do and everything that you weren't supposed to do. But then after surgery, it was a little bit like, "I don't know what's going on here."

Amber Tresca (29:39):

And I remember going into my surgeon's office and literally asking him very pointed questions so that I could get those answers because I needed to move on with my life. What did you do, Danielle, when you had to ask those questions about the more difficult or personal or intimate topics?

Danielle Gulden (29:56):

So, for me, the misdiagnosis for a long time was really stifling, I guess you can say. So, once I received the proper diagnosis, I think I was just an open book that I had an answer and I had a team that was willing to listen to me. And I recognize that. So, I know I'm the minority on this because I think I'm very blunt and I am really out there. And like I said, I want to fix everything as soon as I can, or work on that.

Danielle Gulden (30:25):

So, for me, it was just getting right down to it. As soon as I walked in, I had my list of questions, again, on my notebook, and nowadays on the iPhone, and just getting right in there. I'm definitely not a very shy person, as you may have guessed. And I always joke that my filter had been taken out a long time ago. So, I think that's good for me as a patient to be able to not beat around the bush and have to have my doctor interpret. "What are you trying to say to me?"

Danielle Gulden (30:58):

I'm right out there. Let's get to it. And I make some little bit of humor with that. I think that's an open door then. Because although these illnesses are not funny, there are many things that years later, you find funny, and sometimes you can find funny at that moment.

Danielle Gulden (31:17):

I think that just also helps not only your medical team, but just to bring down that barrier for yourself. Take down that wall, so that you can just be open and honest and get right to what you need to be talking about.

Amber Tresca (31:30):

Yeah, I think that's right. Dr Bernasko, I just want to ask you if you have any advice for patients on, if they don't have a provider that's all up in and asking them who they're dating and how they're doing like you do, how can they start those conversations and better advocate for themselves?

Dr Nana Bernasko (31:47):

So, when it comes to being an IBD warrior, that's what I call my patients, they're all warriors, right, one thing that I do empower them to do is to be open communicators. I always tell my patients, "I cannot fix what I don't know. I cannot read your mind."

Dr Nana Bernasko (32:03):

And when I come into clinic, I have my own agenda. I do write notes for things I need to accomplish. But I also ask that question, is there anything else that we need to talk about today that you came in with? I think it also falls back on the provider to, again, create that safe space and ask questions of the patient, not just come in with our own agenda. So, that's one.

Dr Nana Bernasko (32:27):

But I always tell my patients, "Tell me the truth. Be as open as possible. You can cry in here. You can cuss in my building. So long as you're not cussing on me, I'm okay. This is your space. But I want you to be as open as possible. We're here to be vulnerable. I'm here to help you. And I can't if I don't know what the issue is." And I always tell, "I don't read minds." It's not one of the skills that I have.

Dr Nana Bernasko (32:53):

So, always empower patients, again, through education and just giving them a voice. I always like to hear them. And I let them know that your feelings are very much appreciated and also respected. And again, talk to me. I can't fix what I don't know.

Amber Tresca (33:09):

If only we could read minds. But that would be a blessing and a curse, wouldn't it?

Dr Nana Bernasko (33:12):

Totally.

Danielle Gulden (33:12):

I feel like nobody wants to read my mind. I'm just going to put that out there.

Amber Tresca (33:20):

Yeah, I'm not sure that I would either want that responsibility or have someone else to have the responsibility. It would make things easier at times. Danielle, so for our newly diagnosed patients, do you have any advice on navigating those first couple of years?

Danielle Gulden (33:37):

Absolutely. I think I'm a big fan of social media. However, I feel very strongly that we need to educate the newly diagnosed patients or even those who have been at it for a while just get stuck in the situation, don't compare your journey to other people, ever.

Danielle Gulden (33:59):

IBD is like a fingerprint, right? We're all different. We could have similar personalities, but does not mean our diseases are going to be the same or journeys are going to be the same, treatment plans, none of those things, medications. What works for me may not work for somebody else. And I feel that so many people...

Danielle Gulden (34:19):

Like I said, social media is wonderful. Support groups are wonderful. Talking to other people are wonderful. Knowing that you're not alone is wonderful. However, you cannot compare yourself to other people's journeys. It's unfair for you.

Danielle Gulden (34:31):

And I think working with your medical team is the most important. You can get all the lifestyle hacks, IBD lifestyle hacks, that kind of stuff, but do not compare your actual medical journey to other people's.

Dr Nana Bernasko (34:44):

I have to echo this same sentiment, Danielle. I always tell my patients, "You're very unique." Support groups are great, but don't get your medical advice from those avenues just because you're different. And how you present and how you respond to medications is completely different. So, you just know that you're unique person and your disease is unique to you. So, definitely agree with that.

[MUSIC: About IBD Piano]

Amber Tresca (35:21):

I'm going to go with you for a sec, Dr Bernasko, because I told you that I didn't give you the question beforehand, and I don't want you to feel stressed about it.

Dr Nana Bernasko (35:29):

Thanks.

Amber Tresca (35:32):

So, I was going through your Instagram account, and I saw that you have something that's called the wall of gratitude.

Dr Nana Bernasko (35:41):

Yes.

Amber Tresca (35:42):

So, I would love for you to tell us more about your wall of gratitude.

Dr Nana Bernasko (35:45):

Okay. I know we're talking, but I do have a wall of gratitude in my office. And it's all the thank you cards and most of the thank you cards that I was able to keep with me throughout my career that would fit on this wall. And I think that sometimes, patients forget that we as providers are also human beings, and we have emotions. And we go through life too.

Dr Nana Bernasko (36:12):

And so, on my tough days and days that I feel like I'm completely beaten down, whether it's struggling with a difficult patient, or I'm just really overwhelmed with life in general, I come to my wall of gratitude. And these are, again, thank you cards from patients from my career that have taken time to send me a card to say thank you for helping them throughout their journey.

Dr Nana Bernasko (36:38):

So, it's from, "Thank you for getting me into remission to go see my family in a different country. Thank you for helping me to take a trip to go adopt my son." It's everything from just even teaching me how to manage my disease.

Dr Nana Bernasko (36:53):

And so, I keep that on my wall, again, just to keep me going and helping other people because I know that what I do is very important to the people that I do it for. And it just makes them better at life and get things done that they weren't possibly thought they could have done in the future. So, that's my wall of gratitude.

Danielle Gulden:

I'm not crying, you're crying.

Amber Tresca (37:17):

Right? Thank you for sharing that on Instagram. And thank you for sharing it with us just now. I hope that you share more of those high points, more of those highlights. I think that they're really important and important for us as patients to see too that people do well, and that they do well enough that they thank their team for it. So, that's fantastic.

Danielle Gulden (37:40):

That's awesome. I may have to take a little bit of that back to Joe with Double Baggin' It because that's a brilliant idea. And we've received some correspondence that we just hold very dear to our hearts. And I think that's a beautiful way to put it out there and to remind yourself. That's awesome.

Dr Nana Bernasko (37:58):
Thank you.

Amber Tresca (38:00):
Danielle?

Danielle Gulden (38:00):
Yes?

Amber Tresca (38:01):
Because we know each other and we're friends, I know that you have embarrassing stories about your life with ulcerative colitis. You're not shy about telling them. I'm curious to know if you have any that I haven't heard yet, though.

Danielle Gulden (38:15):
You may have heard this one, but I was reminded of it this morning. So, I'm going to tell you a little post ostomy story. So, I have an ileostomy. I've had it for 14 years. And it's a wonderful thing. I enjoy my ostomy very much. And I became very complacent. So, I went to Starbucks earlier. And this is what reminded me of the story because it's an integral part of the story.

Danielle Gulden (38:38):
In my first 10 years, I'm very fortunate. I have a wonderful little stoma and I have very few issues, if any, honestly. I'm extremely fortunate. And so, you can forget about that and this event could actually happen with or without a butthole. Let's put that out there. This story could happen to anyone with or without. So, I just happened to be without and with an ostomy.

Danielle Gulden (39:00):
And so, one day, I was enjoying a little me time. Dr Bernasko said, "You got to have your me time." Right? Mental health is good. So, I decided that I was going to go to the Columbus Zoo by myself without husband or child, with no friends involved.

Amber Tresca (39:17):
Okay, I do that too.

Danielle Gulden (39:19):
So excited. Here's another part of the story. I just started a new medication for a different illness that I deal with. And I was unaware of some of the side effects. Throw that in with the bucket sized iced latte and some leggings. It's like going into fall, had my hoodie, my little

backpack, which one would think that you would carry essential then. You would think that incorrectly. You would absolutely think that incorrectly.

Danielle Gulden (39:51):

And so, there I was enjoying my me time next to the polar bears and the brown bears, enjoying them. And when I felt a strange little sensation, a little warmth and then a little cold, I was like, "What might that be? What might that be, Danielle?" So, I head over to the bathroom confidently. "That can't be anything. I just spilled a little coffee. Oh, it could be something. It could be something."

Danielle Gulden (40:18):

I had a blowout of all blowouts with my ostomy. That never happens. Hence me not carrying supplies, which kids, if you're listening at home, whether you have a butthole or not, take extra underwear. Bring extra toilet paper. If you have an ostomy, bring extra supplies. You just put in a little Ziploc. It's not difficult. Just like a diaper bag for a baby, but then you can put it in a Ziploc. What's wrong with you, Danielle?

Danielle Gulden (40:44):

And so, I furiously start digging through my little Adidas backpack thinking maybe by some miracle, there's some kind of thing in here. There was not. There was lots of chopstick. And so, here's the fun part.

Amber Tresca (40:58):

You thought you were normal.

Danielle Gulden:

I don't even know why.

Amber Tresca:

You thought you were having a normal day.

Danielle Gulden (41:03):

I don't even know what to think. And then, I'm like, "Oh my gosh. I just started this medication. This is probably it." We're talking not just like, "I eat too many almonds thick poop." I'm going to get gross here. I'm going to like, "Listen, we're going to have it out. I'm talking poop fountain, a poop fountain."

Danielle Gulden (41:18):

And so, I'm like, "Oh my gosh. This better not be one of those, the newer bathrooms of the zoo. I don't want the forced-air hand dryers. I want toilet paper. I want the paper towels. I want all of that." So, thankfully, they did have that. I went and grabbed a bunch. I shoved them in where I had to, tied the sweatshirt around my waist.

Danielle Gulden (41:40):

But the best part is I am the furthest point in the zoo from the entrance, the furthest as far as you can be. Because I knew once I got to my car, it was the promised land, right? You just drive your little self home and you're going to be fine. I, in the furthest point, and then it is during the week. And so, there are a lot of moms with strollers.

Danielle Gulden (41:59):

And it was like an old school game. Back in the pioneer days, old school game of Frogger where you had to get away from all of the small toddlers and children who were still my height. That's right. They were still my height running at me, happy to see the bears.

Danielle Gulden (42:14):

And I literally put my hand on somebody's child's head because, just he wasn't looking, that would have been a mess. I'm not going to say what I really think it would, but it would have been a storm. A storm, let's just call it that. And so, anyways, I had learned my lesson that day as I had been.

Danielle Gulden (42:33):

It was very similar, right? When you have to go with IBD before an ostomy, when you're doing that marathon sprint with your butt cheeks put together, I was doing the sprint, holding on to my belly realizing, "Danielle, you're going to go make 5000 emergency ostomy kits to place everywhere that you go. I wanted to give one to each of my friends, put them in my car, put them in every backpack, every purse." I was thinking ahead.

Danielle Gulden (42:57):

And I've done many posts about this on Double Baggin' It because everyone needs a little emergency kit. Anyways, it was not funny at the time. It was super funny once I got to my car, but it really was a game of Frogger with strollers. And now, I have a little bit of zoo PTSD sometimes, which is in a funny way.

Danielle Gulden (43:14):

Not that PTSD is funny, but I get there and I see a lot of strollers and I'm like, "Oh, I just thankfully just changed my bag this morning. We're good. I have all of my supplies." But it was a learning experience. But it was also very funny because it was just everything that could go wrong went wrong.

Danielle Gulden (43:31):

And then, you top it off with the bucket size of the iced latte. That's never a good idea for anyone. Anyone, wherever you may poop, whatever area of the body you poop out, that is not a good idea. You need to plan ahead and maybe just get the smaller one. Anyways, that's my story. And it's all about learning. So, people, be prepared.

Amber Tresca (43:54):

Sometimes we have to learn things the hard way in order to never do them again.

Danielle Gulden (43:57):
Be prepared.

[MUSIC: IBD Dance Party]

Amber Tresca (43:59):
Danielle, Dr Bernasko, thank you so much for coming on About IBD and sharing all of your wisdom, some of it, very hard one, and the tips that you have for helping people deal with the complications of ulcerative colitis and living a better quality of life. I really appreciate your time.

Dr Nana Bernasko (44:17):
Thank you so much.

Danielle Gulden (44:19):
Thank you. It's been very fun.

Amber Tresca (44:26):
Hey, super listener. Thanks to Dr Nana Bernasko for bringing her knowledge and perspective to this topic and all she does, not only for her own patients, but for the patient community as a whole by teaching other health care professionals. Thank you also to Danielle Gulden for being so transparent about her journey, and for always making me laugh.

Amber Tresca (44:44):
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 108 page on aboutibd.com. You can also follow me across all social media as About IBD. Thanks for listening.

Amber Tresca (45:03):
And remember until next time, I want you to know more about IBD.

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