About IBD Podcast Episode 114

How to Be Happy & Healthy With IBD: Common Misconceptions About IBD

Myths and misconceptions about IBD are common. Even amongst patients, there's things that take time and education to understand because the things that swirl around in the public consciousness are not always true. To help understand why we can't get rid of some of these common misconceptions, Amber Tresca is joined by gastroenterologist and IBDologist Siobhan Proksell, MD, and ulcerative colitis and irritable bowel syndrome (IBS) patient advocate Molly Dunham-Friel, MPH of Better Bellies By Molly.

Concepts discussed on this episode include:

- IBD Parenthood Project
- How Gut-Directed Hypnosis Helps IBS, IBD and Other GI Disorders
- What Is Perianal Crohn's Disease?
- Does Stress Cause Inflammatory Bowel Disease?
- Hypnotherapy as an IBS Treatment Option

Find Siobhan Proksell, MD on Twitter, and at University of Miami.

Find Molly Dunham-Friel, MPH at Better Bellies By Molly, Facebook, YouTube, Instagram, and LinkedIn.

Find Amber J Tresca at AboutIBD.com, Verywell, Facebook, Twitter, Pinterest, and Instagram.

Credits: Mix and sound design is by Mac Cooney. Theme music, "IBD Dance Party," is from ©Cooney Studio.

Episode transcript and more information at https:/bit.ly/AIBD114

Listen and Subscribe:
Apple Podcasts | Spotify | Google Podcasts | Overcast | Stitcher | Castbox

---

[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 114. About IBD is excited to be partnering on this new limited podcast series, How to be Happy & Healthy With IBD.

Amber Tresca (00:25):
I think one of the ways that the IBD space is unique is that there are so many myths and misconceptions. Here are just a few of the ones that I've heard over the years. Number one, people with IBD make themselves sick with stress or nerves. Number two, people with IBD can't or shouldn't become parents. Number three, IBD is the same as irritable bowel syndrome or IBS. Number four, ulcerative colitis is less serious than Crohn's disease. Number five, IBD is caused by a poor diet.

Amber Tresca (00:58):
These are only a few, and they are all false. But here's the question, how do we go about letting people know when they have their facts wrong? To set the record straight, I talked to Dr. Siobhan Proksell a gastroenterologist at the Crohn's & Colitis Center at the University of Miami, and Molly Dunham-Friel, ulcerative colitis patient, and founder of Better Bellies by Molly. They tell me how IBD myths affect patients and what we can do about them.

Amber Tresca (01:24):
Our topic is common misconceptions about IBD. There are so many myths, but even as a long term patient myself, I feel like I'm still hearing new ones all the time. For that reason, I've asked two guests to come and share their knowledge and experience with me is Dr. Siobhan Proksell, assistant professor of clinical medicine at the University of Miami Miller School of Medicine. Dr. Proksell, thank you for coming on about IBD. Would you take a minute to introduce yourself?

Siobhan Proksell, MD (01:54):
Absolutely. I'm happy to be here. As Amber said, my name is Siobhan Proksell. I am a gastroenterologist at the University of Miami, and I specialize in inflammatory bowel disease. I did all of my training up in Pittsburgh, but I'm originally from the South Florida area. So I moved back last year, and now I'm working with a great group at the Crohn's & Colitis Center at the University of Miami.

Amber Tresca (02:19):
Thank you so very much. Also, I have with me, Molly Dunham-Friel, ulcerative colitis patient, and the founder of Better Bellies by Molly. Molly, we've worked a little bit together in the past, but I'm excited to get to know you better today. So thank you so much for coming on. Would you introduce yourself for just a minute?

Molly Dunham-Friel, MPH (02:38):
Sure. Thanks, Amber. Like Amber said, my name is Molly Dunham-Friel. I am an ulcerative colitis patient and I've had a IBD since 2012. I also live with IBS. I'm now a patient advisor, and like

Amber already said, the founder of Better Bellies by Molly, which is really my platform to improve lives for who live with IBD and IBS. I'm so excited to be here today.

Amber Tresca (03:04):
Thank you so much. I'm really looking forward to your perspective. I told you before that you were the patient for this topic. So I can't wait to hear what you have to say.

Amber Tresca (03:14):
So I'm going to start with you Dr. Proksell. We know that there's a lot of misconception about IBD amongst the general public. So what are some of the ones that you've heard in your practice?

Siobhan Proksell, MD (03:26):
I think when patients come and see me, the two biggest misconceptions that I hear are, one, they did something to themselves to cause it, and it's their fault. They're always asking, "What did I do? What could I have done differently?" And then the second is a little bit more sex specific, but along the lines of many women feel that because they now carry this diagnosis, they are unable to get pregnant or cannot have a safe or healthy pregnancy because of it. They think those are two very, very big misconceptions that I hear weekly, I would say, in my practice, when I'm seeing new patients.

Amber Tresca (04:05):
Wow. It's always a little bit surprising to me because for myself, I don't think I've ever spent a minute thinking that I did something to give myself IBD. Maybe I'm alone in that. And as the co-founder of IBDMoms, this is something that we work at every day is to help people understand that they can get pregnant. They can have a healthy pregnancy. They can have a healthy baby, even though that they're living with IBD. So thank you so much for your work in that area, because it's really, really important.

Amber Tresca (04:34):
Molly, most IBD patients have had to field a lot of IBD myths from friends and families, sometimes coworkers. What are some of the ones that you've heard?

Molly Dunham-Friel, MPH (04:44):
Sure. I actually was getting my hair done the other day. And I told the hair stylist that I had IBD, and she said, "Oh, so you can't poop." And I said, actually, "No, that's not..." I was like, "Yes, for some people that is the case. But for me-

Amber Tresca (04:59):
That's true.

Molly Dunham-Friel, MPH (05:01):
... that is not really. It's more the opposite for me." But that was one, you can't poop. You poop all the time. You can't stop pooping. That a lot of people interchange IBD and IBS and start

using them interchangeably, and so that's another one that's really huge. And that you look fine, like disbelief that you have a disease or that you have IBD or that it is severe. I would say, those are the most common.

Amber Tresca (05:29):
That's so funny. How did that come up at a hair appointment? I'm wondering.

Molly Dunham-Friel, MPH (05:34):
So [crosstalk 00:05:35] I think that was because I was explaining that I founded Better Bellies by Molly, and that's what I've been working on. And that I support patients with IBD. And so it just got the conversation rolling. And occasionally it will come up, when I'll say, "Oh, I have IBD, so it's applicable in this way." But I think I was just self-promoting.

Amber Tresca (05:57):
Well, I was going to say, my stylist knows, of course, about what I do for a living, and she knows that I have a podcast. Because as the host of a podcast, I am obligated to tell every single person that I meet, that I have a podcast. That's one of the things that you're supposed to do. Self-promotion, can't get away from it.

Amber Tresca (06:16):
Dr. Proksell, it sounds like your patients tell you about the things that they've heard about IBD that might not be true. Are there times when you have to sort of coax it out of them? Or do they feel a little bit uncomfortable in talking to you about some of the things that they've heard that aren't necessarily true?

Siobhan Proksell, MD (06:35):
I think that it very much dependent on the person. Obviously when I meet somebody for the first time, we're starting to develop a relationship. And typically one of the questions that I ask is what do you know about your diagnosis? What have you heard about it? And what questions do you have about it? Because, I'd like to know what people's perspective is. Some people have a very strong family history of inflammatory bowel disease, and they've had a lot of exposure and a lot of experience with it. And then some people have never even heard of it, right?

Amber Tresca (07:10):
Mm-hmm (affirmative).

Siobhan Proksell, MD (07:10):
And like Molly was saying, confuse IBD and IBS, it's very common and they have a different perspective potentially. I do have many patients ask me if there's anything that they did to cause it. And so I try to elicit an understanding of what they know, what they're comfortable with. And then we delve deeper and deeper into it throughout the development of our relationship.

Siobhan Proksell, MD (07:38):

Some people are a lot more comfortable in the beginning and some people take a little bit of time, and either is completely fine. But it's important to be at a place with your provider, at some point, where you feel like you can talk to them about pretty much anything.

Amber Tresca (07:52):
Perfect. I love that you ask, "Well, what have you heard?" That's such a very neutral way to get that information so that you can dig into it, and understand where they're coming from, and something that you might need to help them understand better. That's really perfect.

Amber Tresca (08:09):
Molly, when you hear misconceptions about IBD when you're getting your hair done, or you're doing something else, or I'm sure through your platform, especially probably through Instagram, you hear these things from people. How do you let people know that what they have heard or what their understanding is might not be correct?

Molly Dunham-Friel, MPH (08:29):
Sure. I try to acknowledge it, their misconception, just with compassion and understanding that, I understand why they might have that misconception. First address it that way, so that I don't come off too harsh. Like, "No, you are wrong," instead, "Oh, I understand IBD and IBS sounds so similar. It's just one letter difference, but two totally different diagnoses. And this is what they are, and how they're different." And I kind of just explain it from that standpoint.

Molly Dunham-Friel, MPH (08:59):
And then I even have those conversations in person. I had one recently, the other day, when I was working out, and I explained, the trainer started following Better Bellies by Molly on Instagram. And he was complimenting everything I did, but he was interchangeably using IBD and IBS as the same thing, and referring to his friend who had Crohn's. And I really couldn't let that go. So I had to say, "They sounds so similar, but they're very, very different." And helping him understand that Crohn's and colitis, like his friend with Crohn's, has IBD and that is very different than IBS.

Molly Dunham-Friel, MPH (09:35):
And so just kind of trying to be personable and compassionate, and address why people have these misconceptions. Just like another misconception is that you can cure your IBD, and that I would say comes across on Instagram a lot. And so understanding, "Oh, I'm so excited that you're in remission. I'm so excited that you don't have any detectable disease. That's so great. But unfortunately there still isn't a cure." And sort of coming at it from a compassionate standpoint.

Siobhan Proksell, MD (10:06):
Cool.

Amber Tresca (10:06):

I think you're really good at that. For myself, I think it's a little bit more challenging. Like I've had someone say to me, "Oh, I don't have IBD, I have Crohn's disease." And I was like, I really wanted to help. [crosstalk 00:10:24] I really wanted to help. I just didn't know how without sounding like that, "Well, actually," person.

Molly Dunham-Friel, MPH (10:31):
Yeah, exactly. Sometimes I come off that way too. I think it's hard, especially when you're answering the same question, addressing the same misconception day after day, it can be hard. Especially when patients who have IBD, don't even believe that they have it anymore, and you can't change their mind. It can be tough, and sometimes you just have to walk away.

[MUSIC: About IBD Transition]

Amber Tresca (11:10):
Dr. Proksell, we know that there's stigma associated with IBD. How do you see stigma around IBD affecting your patients? And do you think it might contribute to delays in diagnosis or in receiving care?

Siobhan Proksell, MD (11:27):
I think stigma can be viewed in a few different ways. One is, a little bit, really, it's the misconception that we were talking about and that you did something to cause it, so it's a problem. And it's a problem that was only self-induced and a lot of people that come to me say, "But I'm so healthy. I'm so healthy and I have no other issues, why is this happening to me?" And there's a stigma around having a chronic disease, first of all. I think that a lot of that can also be very difficult in a work environment as well. Particularly, when you're at first sick and getting diagnosed and needing to use the bathroom regularly. It's uncomfortable, to have to say, "Oh, I have to go. Oh, I have to go again." Get up in the middle of a meeting. It's embarrassing, so those stigmas definitely come across.

Siobhan Proksell, MD (12:19):
I think the other thing that's difficult is a lot of people will initially get diagnosed with other issues, like IBS, before they'll get diagnosed with inflammatory bowel disease. So then, also, there can be a delay in treatment in that regard. And then I think that the other thing in having a chronic illness is people can also be afraid to tell people. And not that it's anybody's business, right?

Amber Tresca (12:46):
Mm-hmm (affirmative).

Siobhan Proksell, MD (12:46):
It's your own personal business about who you want to tell. But many, many of our patients are diagnosed at a very young age, and as they grow and they develop relationships, whether it be

with friends or partners, those are things that can ultimately be hard and difficult to disclose. And I think all of those really play a role in seeking care as well.

Amber Tresca (13:10):
Molly, has there been any times, I know the answer to this is, yes, but have there been any times when you've experienced some stigma? And what did you do? How did you handle it?

Molly Dunham-Friel, MPH (13:20):
Sure. I would say it's hard not to live with IBD for 10 years and feel stigmatized in some points in the journey. I feel like I've experienced stigma from everything from a friend to a coworker to healthcare providers, even gastroenterologists, actually. And when it came from, some of the gastroenterologists that I had early on, they would just dismiss me. And I think it's really hard sometimes to feel heard, and to not just feel like you're complaining or you're a hypochondriac of some sorts, because you can't really see your disease, even though they of course had it on my colonoscopy.

Molly Dunham-Friel, MPH (14:05):
So I feel like I felt stigmatized maybe as just like a young female early on in the diagnosis, especially, when I was previously seeing a male provider. And then also like the looks that you get when you tell someone that you have IBD and IBS, but really when you say I have inflammatory bowel disease, it's the body language that someone sometimes portrays to you that I can't really explain it. There's no word to describe it. I would just describe it as you can tell you're making them uncomfortable and you can tell they're slightly disgusted. And I feel like [crosstalk 00:14:49]... It's especially hard to live with when I was younger now I don't care, but when I was 23, I cared a lot.

Siobhan Proksell, MD (15:00):
Because most people get diagnosed between the ages of 15 and 30, and those are such formative years. I mean, to get this diagnosis, and then go to college is so hard.

Molly Dunham-Friel, MPH (15:13):
Yeah. And especially being young and dealing with the generalization that young people are healthy, young people don't understand what the older people were going through or having to use the healthcare system. I could just remember fighting the tears at the workplace, because everyone just dismissed me. They didn't know what was going on with me. I wasn't ready to talk about it at the time, because I was just getting diagnosed. But the misconceptions, they just fly rampant everywhere. And sometimes you can address them by speaking up for yourself, and I do that now. But sometimes it's easier to just walk away and not engage in the conversation. So I think, if you're a patient, just listen to your gut and just follow your intuition in the moment.

Amber Tresca (16:02):
I just didn't tell people [crosstalk 00:16:05], literally, that's how I got through college is I didn't tell people. Because the couple times that I did, I've never broken it down quite in that way,

uncomfortable and also disgusted, but you are absolutely correct. That is the look that you see in people's eyes. And then once they get over that, and then you see a little bit of wheels turning behind their eyes, and then sometimes you get a really bizarre a question that has nothing to do with anything. And there's no way to anticipate what it's going to be, and some of them are wild. And so as a consequence, I think my defense was just to not tell people, unless they really, really, really needed to know.

Siobhan Proksell, MD (16:50):
I think a lot of my patients will even do that, because I'll offer to write a note for work or to fill out paperwork. And they're like, "No, no, no, it's okay." And I was like, "I really think you need to have this in place, so that you can get those accommodations that you may need." And most of the time, eventually people will come back and ask for everything to be filled out, or just to make sure that if something happens in the future, then we're not flying by the seat of our pants, trying to get things taken care of. But it's a really, really tough thing, because it's so personal.

Molly Dunham-Friel, MPH (17:25):
It is. And I do feel like that's the difference between when I was first diagnosed and I wasn't feeling like an empowered patient. And then now over the years becoming an empowered patient and feeling like I have a voice at the table. And that's part of why I started Better Bellies by Molly, which is to help other patients feel empowered, to feel like, "Oh, yeah, Dr. Proksell, I really need that letter. I'm going to talk to my employer," or, "I'm going to let these folks know about my disease and I don't need to be ashamed in it." And so I learned that over the years. And so now I'm trying to help other patients learn that. And it sounds like you're doing that in your clinic, which is awesome.

Amber Tresca (18:06):
Molly, do you have an elevator speech that you give?

Molly Dunham-Friel, MPH (18:10):
Oh, yeah, a little bit. I mean, it's not refined or anything, but elevator speech is, I have ulcerative colitis, which is a type of inflammatory bowel disease, commonly known as IBD. There's two main types of inflammatory bowel disease, Crohn's disease and ulcerative colitis. There are other types, but Crohn's and colitis are the most common. And I have ulcerative colitis. I also have IBS, which stands for irritable bowel syndrome, which is a completely separate diagnosis, not related to my IBD.

Amber Tresca (18:44):
Very nice. And then that idea that IBD and the IBS can occur in the same person at the same time, I think that's wild. First of all, that's wild. But then also to have other people wrap their head around that as well can be really, really challenging. So I love that you include both of those things to try to help more people understand how these condition affect you and can affect other people too.

Molly Dunham-Friel, MPH (19:13):
Occasionally, I will go over like how the inflammation in Crohn's is continuous and can affect anywhere from the mouth to the anus versus ulcerative colitis is just in the colon. Sometimes I go into that detail and other times I don't, it depends on the audience.

Siobhan Proksell, MD (19:29):
I did it today, because I was teaching med students. I always start off asking them if they know the difference between IBD and IBS.

Molly Dunham-Friel, MPH (19:38):
Do they?

Siobhan Proksell, MD (19:40):
Maybe one person does, but not really. And I don't expect them to, and I've done this for like students in occupational therapy school and a variety, and frankly, some people work with don't necessarily know the difference either. So I make sure we clarify that and then we kind of go down the line, but it's always fun.

Molly Dunham-Friel, MPH (20:00):
Well, thank you for educating them.

Amber Tresca (20:03):
That's awesome.

[MUSIC: About IBD Transition]

Amber Tresca (20:24):
Yeah. And then, obviously, it's really clear that patients and doctors need to be in this together to do myth busting. So Dr. Proksell, you've already explained how you teach other people about the differences, for instance, between IBD and IBS, and then the differences between Crohn's disease and ulcerative colitis. So what is your advice to other healthcare professionals about how they can recognize these myths and misconceptions and how they can get accurate information to their patients?

Siobhan Proksell, MD (20:58):
I think that in speaking to patients, and first of all, you need to listen to them and you need to understand where they're coming from, and you need to understand where they got that information. And sometimes it's just confusion, you misunderstood what they were saying or vice versa. But I find that one, obviously, when you are seeing patients and you're not a gastroenterologist, you're not an IBD provider, and you're concerned that something is going on, listening to their history very carefully is obviously important.

Siobhan Proksell, MD (21:35):

The other thing I'll say is that IBS is a diagnosis of exclusion as well. So if somebody walks into your office and has had no work up whatsoever, you really need to start to delve deeper into why things are happening. Because I think there's many, many things that can possibly occur,

Siobhan Proksell, MD (21:53):
In terms of misconceptions, whenever my patients tell me something that I find to be a common misconception or just a misconception in general, I ask them where they got the information from. And then a lot of them will smile and they'll be like, "Facebook [crosstalk 00:22:12]," or something like that. And I was like, "Well, how reliable do you think it is?" And they're like, "Eh, again, anyone can post whatever they want." And so then we always circle back to things like the Crohn's & Colitis Foundation or resources that are more reliable, IOIBD, and then some of the conferences too, they're really starting to involve patients a lot as well. So all of those things we kind of circle back to.

Siobhan Proksell, MD (22:36):
But we do, we delve into it. We think, okay, who put up this information? Why might they have put up this information? Do they potentially have a secondary gain from posting this? Are they selling something? So we kind of look at it from that perspective. And sometimes there's really, really great points that are just not typical Western medicine that I think are really, really good things to consider. And then sometimes there's things that are like a little bit of fear mongering and off the wall. And those are the things that really concern me, because I don't want my patients to be afraid. And I don't want them to do things that are dangerous. But I also want them to know that they can come and talk to me about things, and tell me what's going on with things, and what their questions are and what their concerns are.

Siobhan Proksell, MD (23:26):
And is this something that I could try? One of my patient and just sent me a message with a picture of this like new vitamin supplement. And I was like, "Well, send me the ingredients. Let's see what's in it. Let's see what it looks like." It's just a multivitamin that someone was trying to market to IBD people, so I think the important thing is making sure that your patients are comfortable talking to you about these things, and then gauging, what is potentially dangerous? And then what is not dangerous and might not have great data for being effective, but could potentially help?

Siobhan Proksell, MD (24:02):
We do a lot of dietary research at UM, obviously, and so if you ask somebody like a decade ago or 20 years ago, they'd say, "Oh, diet has nothing to do with this." But for a lot of people, it plays a big role. If you have chronic inflammation and it takes a while to get things under control, then you can have leftover nerve damage from it as well. So gut focused hypnosis is a really great way to address something like that.

Siobhan Proksell, MD (24:27):
So there's many, many different avenues to pursue. And I think the thing that upsets me the most is when someone tells me, "Oh, I brought this up to my other doctor and they basically

wouldn't acknowledge it or told me something was all in my head." And I'm like, "Well, the guy and the brain are very well connected, but..." And I think just exploring everything is really important.

Amber Tresca (24:55):
Yeah. I think one of the things that often gets lost in the harms, you can say, "Well, there's no harm in trying it," but sometimes these things that people want to try cost money. And to me, that's a harm, that can be a harm. That it's something that you invest your time and money in, and then it doesn't work for you. So that's something that I tell patients sometimes that it's like, "Okay, but think about it from all of these angles, not just evidence, it might work, or it might not work, but also, your cost, the time that you're going to spend doing it, things like that."

Siobhan Proksell, MD (25:36):
Those are huge factors as well.

Amber Tresca (25:38):
Molly, do you have any tips for people with IBD or IBS as they navigate these conversations when they're with myths or with stigma? You already said that you like to approach it with compassion, which I love. Are there any other things that you do?

Molly Dunham-Friel, MPH (25:54):
Sure. In addition to leading with compassion, I also try to inform and educate, and then I also try to acknowledge the parts that the person got right. So if they got part of what they're talking about accurate, I try to address that, even if that's just to cushion the blow of before you explain to them what they didn't get right. Just taking that approach, but then also using your patient voice and being a leader and feeling like empowered enough to educate other people with that compassionate sense.

Molly Dunham-Friel, MPH (26:33):
You don't need to come off as if you know everything. Nobody knows everything, but just speaking from the heart and speaking from your lived experience. Because nobody can take away or discredit your lived experience, and that can't be taken away or discounted. And so use that knowledge to help others and to help address these misconceptions and to reduce stigma by speaking up for yourself, when you do feel comfortable. It can be very empowering, actually, to stand up for yourself.

Amber Tresca (27:06):
I agree. Dr. Proksell, you mentioned the International Organization for the Study of Inflammatory Bowel Disease, which is the IOIBD, and the Crohn's & Colitis Foundation. Are there any other resources that you like to share with patients to help them understand IBD? And then what could be a myth and then what could be true?

Siobhan Proksell, MD (27:27):

I think those two are probably my most referred ones. I also refer to the IBD Parenthood Project quite a bit as well. I really, really like that resource, because, again, we're diagnosing patient who are very young, many of whom at some point in their lives are interested in having children. So I find that that's a very, very good resource. Because once you start to Google IBD and having kids, you could go down a deep, dark, scary black hole. And so I want to make sure that all of those are good resources.

Siobhan Proksell, MD (28:04):
I also like the fact that Crohn's and colitis has a lot of support groups, essentially, wherever you are. So one of our dieticians runs the support group down here, and I find those to be helpful. At my prior institution, we also had patient advocates and patient representatives that were embedded with our team. So we had this peer-to-peer network that we would refer to when patients were first diagnosed, which was very, very helpful. Or something had changed and they were potentially needing a surgery or a big shift. And so I think that having those types of resources are excellent.

Amber Tresca (28:50):
I found that the one-on-one, like when my surgeon connected me with another patient who had a j-pouch, and of course this was in 1999, so there was no social media, but connecting me with somebody who had been through it already was probably the most impactful. Because I asked my surgeon all of the technical questions and he could tell me how things were going to go and how many days in the hospital, and how many days at home and what about work and whatever, but this other gal could tell me about what her life was like. And I loved my surgeon, but he didn't have j-pouch, he couldn't tell me life was like as a young woman.

Siobhan Proksell, MD (29:30):
Right, we can only say so much. I think that one thing that people have a lot of concerns about that they are very afraid to bring up are intimacy issues. And there's, I think ,two parts to this. One part is when people get diagnosed at a young age and their parents accompany them to their appointments all the time. I'm an adult gastroenterologist. I technically see adults. I see many, many patients with their parents. And at some point, once we are in a place that's a little bit better or potentially in a place that's a little bit worse, and they're scared, I really want to have that conversation with people.

Siobhan Proksell, MD (30:16):
So I've kicked parents out of the room before in a very, very nice way. Because their kid is not going to want to have that conversation in front of them at 26 years old, and one of my patients was 26 or 27, and I had her parents leave. And she was like, "That's the first time anybody's ever asked my parents to leave an appointment, so they could talk to me about these things.: And it's a big deal with IBD in general, whether or not you're flaring or you feel good, or you have perianal disease, or there's an ostomy, there's so many different things that can affect it. So that's a huge thing that I think is hard to talk about. And you really, I feel like, need to devote a lot of time to it, which is tough in our current healthcare system. But that's one thing that I had wanted to mention earlier.

Molly Dunham-Friel, MPH (31:09):
And that's a great thing to bring up, no provider has ever mentioned it to me, anything about intimacy. No one's asked me and I've had IBDs from 23 to 33 so far, and it's never come up, unless I've said something myself, which is a little shocking. But I'm glad you brought it up, and I'm so thankful you're talking to your patients about it.

Siobhan Proksell, MD (31:31):
I think it's really tough. And it's really not something that I can necessarily build into a regular visit all of the time. But there are certain scenarios in which I make it a point to bring it up, or I can get from some insinuations during an appointment that it's an issue, and I'll flat out ask. It's something that we used to like collect some data on as well. So if we had that information, we knew in advance and could take a look at it. But part of the issue is you have so many things to talk about in such a short period of time that it kind of starts to fall to the wayside. And I really think it's something that we as providers need to work on, myself included. This is not something that I asked during every visit, and it's something that I really need to start to add in, again.

Amber Tresca (32:34):
The day that I marched into my surgeon's office and had to ask him that question, "Okay, the staples are out. When can I have sex with my husband?" And it was just like, it wasn't brought up otherwise, no one ever brought that up. Not pre-surgery not my stoma nurse, nobody. So it was up to me, and you have to ask. And I think asking other patients can help you get a certain amount of information, but I really feel like at the end of the day after you've had surgery, or if you have something like perianal disease, your doctor really needs to weigh in on things like that and needs to give you some guidelines or some framework to work with.

Molly Dunham-Friel, MPH (33:18):
Absolutely.

Amber Tresca (33:20):
Molly, same question for you. Are there any resources that you like to send patients to when they're learning about IBD or there's a myth or a misconception that they're dealing with?

Molly Dunham-Friel, MPH (33:30):
Oh, sure. Well, I use the Crohn's & Colitis foundation website all the time. I commonly will drop links into a chat or into a DM to send them directly. I also agree with Dr. Proksell on the support groups. I also was a moderator for three years for one of the Crohn's & Colitis Foundation support groups. Now, they are mostly online, so they are accessible to so many more people now. Don't be afraid to go. I remember how I was nervous to go to my first support group about five years ago, but it was the best choice that I ever made. And I met so many great people and are still connected to them today. But mostly the Crohn's & Colitis Foundation, in terms of reputable sources for IBD, specifically, there's so many other great websites out there, but that's the main one that I point people to on a regular basis.

[MUSIC: About IBD Transition]

Amber Tresca (34:32):
Dr. Proksell, I'm wondering, is there anything coming up for you, fun, now that hopefully we're in a better place and people can travel more and do more things? What are you looking forward to this spring?

Siobhan Proksell, MD (34:43):
Well, some people might define it as fun, some people might define it as a little bit more work, but I'm having my second child in a couple months, so we're excited. It will be lack of sleep and that whole thing, but it'll be an interesting and transition, so we're excited for that.

Amber Tresca (35:05):
Yeah, it's worth it. The second one is, that's like, it's a kick in the pants, I got to say. But seeing your kids interact with one another, I mean, there's just no... Anybody would be willing to go without sleep for that, you know?

Siobhan Proksell, MD (35:19):
Yeah.

Amber Tresca (35:21):
Molly, I'm sure that you have one, is there an embarrassing or funny story about your IBD or your IBS that you could share with us?

Molly Dunham-Friel, MPH (35:31):
Oh, I don't know about funny. Wow. Oh, geez, on the spot. I would say embarrassing, for sure. There's plenty of those. I would say one of the most embarrassing times with my IBD was when I was at the pool, in the pool, and I had to go to the bathroom so bad and they locked the bathrooms at the pool.

Amber Tresca (35:58):
Why?

Molly Dunham-Friel, MPH (36:00):
And so I was in my bikini and all of a sudden I was like, "Oh no, it's happening." I knew that feeling. I was like, "Oh, no." And I had to climb five floors of stairs that were open to the public, in a way, literally, holding my bum, going as fast as I could to get back to the toilet. And I didn't like fully make it, but I almost made it into the doorway. So at least I was kind of in my house, but it was awful and embarrassing. And even though just my now husband, but boyfriend of the time was with me. It was embarrassing. And it was awful. And I luckily was able to kind of make it out of the main audience, but it was still stressful and anxiety provoking and embarrassing.

Amber Tresca (36:54):
Is it funny now at all? Or not yet?

Molly Dunham-Friel, MPH (36:58):
I would say it's been enough time that I can definitely laugh about it now. That's a good thing, and-

Amber Tresca (37:04):
Okay, good.

Molly Dunham-Friel, MPH (37:04):
... I try to use humor as much as I can to get through life with IBD. And it definitely helps., Wouldn't you say?

Amber Tresca (37:13):
Absolutely. There's really nothing else that you can do. Every single patient has an answer to that question, and it is usually a pooping your pants story.

Molly Dunham-Friel, MPH (37:24):
I know. Doesn't it have to be a poop your pants story? But in this case it was poop your bikini, which is like [crosstalk 00:37:31]-

Siobhan Proksell, MD (37:30):
It's another level.

Molly Dunham-Friel, MPH (37:34):
... mystery there. Luckily, I was wearing black that day.

Amber Tresca (37:41):
Thank you so much, Molly, Dr. Proksell, I really appreciate your time and your perspective on talking about myths and misconceptions around IBD, and how we can educate people and help them become more empowered patients and learn more about these diseases. Thank you both so much for coming on about IBD.

Siobhan Proksell, MD (38:03):
Thank you.

Molly Dunham-Friel, MPH (38:03):
Thank you.

Amber Tresca (38:10):
Hey, super listener, thanks to Dr. Siobhan Proksell for sharing her knowledge and experience with IBD myth busting. As an educator, she's working to make sure healthcare providers

understand what's true and what's not when it comes to IBD. You can follow her on Twitter as @SiobhanIBD, and that is spelled S-I-O-B-H-A-N-I-B-D.

Amber Tresca (38:32):
Thank you, also to Molly Dunham-Friel, who is both educating and making us laugh about IBD and IBS. You can find her on her website, betterbelliesbymolly.com and on Instagram and Facebook, as @betterbelliesbymolly. 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 114 page, on aboutibd.com. Thanks for listening. And remember until next time, I want you to know more about IBD.

Amber Tresca (39:05):
The American Gastroenterological Association and About IBD "How to be Happy & Healthy With IBD" podcast series is supported by Arena Pharmaceuticals.

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.