About IBD Podcast Episode 107

Colitis Conversations: Getting an Accurate Diagnosis

Once people understand that symptoms like ongoing diarrhea and bloody stools are not normal, they need a way to overcome embarrassment and talk their symptoms over with a health care provider. Having an open and honest conversation will help ensure a quicker diagnosis of ulcerative colitis and getting the right treatment.

On this episode, Rasheed Clarke, ulcerative colitis and j-pouch patient and author of Three Tablets Twice Daily and Dr Christina Ha, an IBDologist at the IBD Center at Cedars Sinai, provide support and guidance to patients with IBD symptoms, newly diagnosed patients, and anyone who is looking for a new way to speak with their health care providers about IBD treatments.

Concepts discussed on this episode include:

- Jimmy Kimmel Gets a Colonoscopy with Katie Couric (and Dr Ha)
- The Impact of UC: Quality of Life
- How to Find the Best Doctor for Ulcerative Colitis
- Types of Ulcerative Colitis (UC)
- Signs and Symptoms of Ulcerative Colitis
- Comparing 6 Biologic Drugs Used to Treat IBD

Find Dr Christina Ha at Cedars-Sinai, LinkedIn, and Twitter.

Find Rasheed Clarke at RasheedClarke.com, LinkedIn, and read Three Tablets Twice Daily.

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.

[MUSIC: About IBD Theme]

Amber Tresca 0:05
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.

Amber Tresca 0:15
Welcome to Episode 107.

Amber Tresca 0:18
This podcast is part of the American Gastroenterological Association Colitis Conversations program.

Amber Tresca 0:25
If you've listened to even a few episodes of this show, you'll have heard how some patients travel a long road to getting a diagnosis of inflammatory bowel disease. Some of the barriers in diagnosing ulcerative colitis include how insidious the symptoms can be, and embarrassment over talking about bowel movements.

Amber Tresca 0:42
However, being really clear about symptoms and how they are affecting quality of life is important to getting a diagnosis and the right treatment. To get to the bottom of this topic, I speak to Rasheed Clarke, ulcerative colitis and j-pouch patient and author of Three Tablets Twice Daily and Dr Christina Ha, an IBDologist at the IBD Center at Cedars Sinai. We discuss the ways patients and health care professionals can communicate better, including the information we need from one another to get on the right path.

Amber Tresca 1:14
Our topic today is getting a timely, accurate diagnosis. My guests are Rashid Clark and Dr. Christina Hoff, Dr. Haas, thank you for coming on about IBD.

Dr Christina Ha 1:25
It's great to be here with you and Rasheed. Thanks for having me.

Amber Tresca 1:28
Rasheed this is going to be your second, techhnically third. Since we talked so much I split an episode into two parts with you. Thank you so much for coming back.

Rasheed Clarke 1:38
As always happy to be here. And I noticed that too, because I was looking back at the past episodes in a totally non narcissistic way. Which episodes I was on before. And I noticed that you split into two so yeah, happy to do another episode with you.

Amber Tresca 1:51
Wait a minute, hold up. You did not know that I split it into two. You didn't listen after?

Rasheed Clarke 1:56
No, I did. I just I couldn't remember now cuz it was back in 2019. I think it was I was I just wanted a little refresher. And, you know, remembering how famous I was back then, when I did that two full episodes with you on the pod.

Amber Tresca 2:12

That was such an experience editing, it was one of the most intense edits I've ever done. But it was also the most fun. So I'm looking forward for you to repeat that experience.

Amber Tresca 2:29
So getting an accurate diagnosis, we know that's a huge problem in the IBD space. So Dr. Ha, I want to start this conversation by asking you about the symptoms of ulcerative colitis, because patients might not realize that the symptoms that they're having are not normal, especially if they've been coping with them for a while and they've been normalizing them. Would you please describe the ulcerative colitis symptoms that might bring someone into your office?

Dr Christina Ha 2:57
Absolutely. And you're absolutely right. It's tricky, because it's not necessarily something that just pops up out of the blue, it's a little bit more insidious.

Dr Christina Ha 3:07
So the symptoms may gradually appear and start to build over time. And a lot of people actually tend to get used to it because it's just something that they've rearranged their lives around. But the classic symptoms of ulcerative colitis. And I say classic, because there's also a typical symptoms of ulcerative colitis, are to have bloody diarrhea with some abdominal cramping, and something that's called urgency.

Dr Christina Ha 3:32
And so the tricky thing is, what do we mean by bloody diarrhea? Well, diarrhea, essentially means that your stools are more frequent, the consistency is more loose, it doesn't always have to just be runny watery diarrhea. But if you usually go to the bathroom once a day, now you're going three times a day, and the consistency is softer. And you're seeing blood actually a majority of the time more than 50% of the time, or you're noticing that there's these cues like hey, I have to run to the restroom, or we may be running into some issues. That's urgency.

Dr Christina Ha 4:04
So the rectal urgency where you feel like you need to run to the restroom, you're concerned about having an accident, or you have the sense of incomplete evacuation. Sometimes we call it dry heaves of the rectum, where you go to the restroom and you feel like you're done, but then you have to run back and go up some more. That's actually not one bowel movement, that's three or four bowel movements, and sometimes just blood or mucus come out. So those are usually the initial signs of ulcerative colitis, but then they can gradually build up to include fevers, weight loss, joint pains, canker sores in your mouth, and overall fatigue.

Dr Christina Ha 4:38
So I always tell people don't disregard blood in your stool, especially if it's consistent and persistent.

Amber Tresca 4:45

Yeah, that's one of the things whenever someone tells me that they have blood in their stool. I'm like, That's hold up. Wait a minute, that's got to go and get checked out. Even if you think even if it's happened before. You need to go and get that looked at right away.

Dr Christina Ha 4:56
Because 20 year olds don't get hemorrhoid bleeding all the time. So let's let's just be clear about that. Unless you're in the John for like six hours of your day non stop, you're not having hemorrhoid bleeding all the time.

Amber Tresca 5:09
And that's a very good point. Because people are often told that, I've spoken to so many patients who they are going to their doctor, the thing that they're telling their doctor about the diarrhea, people, I think, sometimes just ignore and normalize or think that they are living with a virus or, or eating right or whatever. But it's the blood that sends them to the doctor.

Amber Tresca 5:29
And then the doctor says something like, well, it's just hemorrhoids, you know. And then whenever I'm talking to someone, my next question is, well, did anyone look? Do you have a rectal exam? And sometimes that answer's no. And I think that's where we can get into these issues where people go for a long time without ever getting diagnosed properly.

Dr Christina Ha 5:47
Absolutely. Because if you don't look, you you can't get an answer. And nowadays, there's even simple things like stool tests, or blood counts or inflammatory markers, that that can actually help understand what the next step should be. Because maybe it is maybe you are the person who just has a hemorrhoid, in which case, let's treat it. But if it's not, let's figure out what it is sooner rather than later.

Dr Christina Ha 6:11
And, you know, although we're talking about colitis, the differential the possibilities also include other things that could be a lot more ominous. I mean, we are definitely seeing, for example, colon and rectal cancer occurring across different age groups much earlier. And there are multiple reasons why but these are certainly things that we don't want to ignore, right?

Amber Tresca 6:29
Absolutely. And Rasheed you are an ulcerative colitis patient, although I know that you like me, you live with a J pouch today. When were you diagnosed? What what year? Or what age were you when you were diagnosed?

Rasheed Clarke 6:42
So I'll give you both it was 2008. And I was 24. At the time of diagnosis,

Amber Tresca 6:49

What sent you to your doctor or what was the final straw? What What made you seek treatment?

Rasheed Clarke 6:55
So basically everything that we were just talking about in terms of the hallmark symptoms of ulcerative colitis, and it was bloody diarrhea. For me, that was the that was the thing that really got me, it really did hit me pretty suddenly, the diarrhea that is, and that was alarming in itself. But then when the blood actually started to appear in the stool, that's when it became more of a warning sign, and the urgency, so the feeling that, you know, I had to go and if I couldn't go in the next few seconds, then an accident was going to happen. And accidents did happen. In fact, before I finally went to see a doctor at a walk in clinic at the time, and the fact that it was urgency, bleeding and frequency.

Rasheed Clarke 7:39
So it was about every hour on the hour, it was really strange that I was able to have the back kind of frequency, almost timed nature of it. But they mentioned the top of the hour, every hour, all day all night. And you would have thought that something before that would have sparked me to go to the doctor. But when it got to that point, that's when I finally made the decision to go seek treatment. And I think the fact that I didn't have a family doctor, when the symptoms arose was maybe a part of the reason why I why I held off on going eventually to a walk in clinic. The fact that I didn't have a family doctor may have delayed things a little bit more.

Amber Tresca 8:21
Yeah, that sounds right. I think that's true. And especially for people like you, you were a young man, you end up in a situation where you have these symptoms, and then you don't know what to do with them. It makes sense that you would go to a walk in clinic, but did they know what to do with you?

Rasheed Clarke 8:39
I get the sense that they didn't. And I'm not sure if it's just you know, from not seeing this an awful lot. It seemed like they went through the I guess what I would have assumed to be the standard process of doing blood tests, stool sample tests, checking for parasites, checking for infections, that sort of thing. All the questions, what have I traveled, have I traveled have I traveled? There's no every time and I can tell you that? No, I haven't left the country the last several years, but okay.

Rasheed Clarke 9:07
And once all those things were looking back negative, then it did feel like there was a little bit of a confusion as to what to do next. And it took a long time to actually get a diagnosis because it took a long time to get test for a barium enema or a colonoscopy, which I feel like should have been done more expediently when when those symptoms came up, and when all the blood testing stool test came back negative. So I think that the delay in getting the proper testing is probably what led to a delay in a diagnosis as well.

Dr Christina Ha 9:39
And you know, if I could jump in, that's we see this all the time. And you know, one of the most frustrating things is that if you've been having symptoms that have been going long, consistently for over two weeks, it is not an infection. It is not just food poisoning, particularly if there's blood in your stool and you're having a lot of frequency in your accidents. It is not a parasite. It's not because those symptoms don't last that long, and many of those are self limited.

Dr Christina Ha 10:05
While you should rule out for infection, especially at a younger otherwise healthy person who's not on immunosuppression yet, that should signal you need to see a gastroenterologist or you need to do some testing to rule out non infectious causes. And I think it's really important because oftentimes, we understandably just, you know, listen and say, Alright, they said, it's an infection, or I should change my diet or take these antibiotics. But it's really important to, to press further and say, Well, you know, what, an infection really lasts as long couldn't it be something else? And when should we look for those other options?

Amber Tresca 10:37
I think that's really important to say, because also, a lot of people seem to think that they have an infection or a parasitic infection. And maybe that's just because that's, like you say, it's self limiting. And that would actually be an easier outcome than dealing with something that is more serious and long term. So just thinking that it's a, it could be a parasitic infection, even though it's common in certain populations, but it's really not all that common.

Dr Christina Ha 11:03
And it's not all irritable bowel either. That also just really gets under my skin because irritable bowel won't present with this kind of bloody diarrhea with urgency.

[MUSIC: About IBD Transition]

Amber Tresca 11:18
We're sitting here, we're talking about these symptoms, because we're two long term patients and a gastroenterologist and we're like, hey, diarrhea, and bloody diarrhea, and mucus and all the things. But these are embarrassing. You know, it was embarrassing to go into the doctor's offices first time and be like, I'm having the bloody poos. Dr Ha. Is there anything that can help patients feel more comfortable? Is there anything that you do or that you've heard that your colleagues do to sort of get people to actually tell you what's going on?

Dr Christina Ha 11:46
So, you know, I try to start every conversation with how can I help you today be and that's the main thing is that we need to set a tone of saying, We're all in this together, we're working as a team. And our goal at the end of the day is to help. And you know, we and I also try not to get right into the heart of the matter right away. You know, we talked about well, you know, tell

me what's going on and describe a little bit more, and I will press and when people say yeah, I'm having a little bit of abdominal pain. I said, Okay, well, tell me about it to a point on your abdomen where it is? And can you describe it? You know, what sort of things have been limited? You know, are you able to get through an entire day of work without using the restroom? How often do you get up at night? In you know, and I even use?

Dr Christina Ha 12:26
Well, this is probably gonna be edited out. But I asked will ask them, you know, can you pass gas without moving your bowels? Can you shart not fart, and that oftentimes lightens up the conversation. And I think it's really about building the trust, because by the time a lot of people see me, they've actually been maybe brushed aside by a number of providers, or been given treatments or recommendations that just haven't worked. And now they're so sick, that part of it is setting the tone, to know that I want to help. And we're not going to stop until we find a solution that works.

Amber Tresca 12:59
I've never had a doctor ask me if I could fart and not shart. But I will say, though that I think that is a really great question. And you don't have to use those terms. Maybe you can use other ones if you feel whatever you're comfortable with and your patient is comfortable with. But no, that's really, really important. And Rasheed and I are both J pouch patients. And we hear from people like us that that is a sort of a delineator sometimes and letting you know how you are whether or not you can actually pass gas. And if you can pass it without sitting on the toilet.

Amber Tresca 13:38
Rasheed, how about you, when you went in and you you saw these folks who you didn't have a family doctor, you didn't have an intimate relationship with a provider and you were going in cold talking to some person telling them about your, your, your bloody boobs? What was that like for you? How did you get through that?

Rasheed Clarke 13:58
Well, it was strange, to say the least, because I'd never talked about that and I think openly with anyone, and it was never something that I had gotten to seek medical attention for before. So I tried to do it in the most like scientific way possible, I guess, to try to make it seem as though like it wasn't like an embarrassing thing. It's just like, I have diarrhea, there is blood in the stool. I have the urge to go this many times per day, like I was trying to be as specific about it as I could, but not to the point of downplaying symptoms.

Rasheed Clarke 14:30
I think I downplayed symptoms when I talked about my symptoms, with non medical people, with family, with friends with colleagues, whoever else but I tried to be as open about the problems I was having. When I talked to doctors and I didn't find it too embarrassing. It was nerve racking in the sense of trying to figure out what was causing it and what could be behind it.

Rasheed Clarke 14:53
And back to what we were talking about a little bit earlier in the parasites I was actually hoping for that because well that's that's something that you can treat, right, I mean, is kind of a one shot. This is a weird thing, I'll deal with it and then move on. If there were nerves from those initial conversations with doctors, it was just from what was actually happening to me and trying to get to the bottom of it.

Dr Christina Ha 15:16
You know, what I will say is, I'm somebody who I'd like, I need the detail. And I like the detail. So I'll tell patients or people I take care of, listen, I'm knee deep in poop all day long. So we're going to get down and dirty about your stool.

Dr Christina Ha 15:28
And you know, I like analogies and I, and it's hard to describe your poop. It really is, you know, everyone says, Oh, I have diarrhea. But I need to know well, what did it look like? So I use analogies it was it pure water? Did it look like oatmeal? What about pudding? That poop emoji soft serve? They look like little rabbit pellets? Tootsie Rolls.

Dr Christina Ha 15:46
And that way we could get because how you present tells us how you're going to respond. Okay, well, it went from watery to oatmeal. Okay, that's not terrible, because there's a little bit more consistency a little bit more form. So maybe we're heading in the right direction. But it went, if it went from you know, a nice log to oatmeal, then that tells me Okay, well, maybe we're heading in the opposite direction, we need to make adjustments.

Rasheed Clarke 16:12
I never realized how many food analogies there were for poop.

Dr Christina Ha 16:17
Gotta love food. And you got to be okay, describing everything with respect to food.

Amber Tresca 16:22
There was a Twitter thread, and I'll have to go back and find it because I don't think I saved it or retweeted it or anything. But there have been several people on Twitter, who have taken the Bristol stool chart and made analogies with food. And in some cases, they've done it for their sort of their local food, whatever country that they're in.

Amber Tresca 16:44
So you know, Dr. Ha might say to somebody, okay, does it look like oatmeal? I mean, I don't know, maybe everyone knows what oatmeal looks like. But in another country, maybe they use a different food to describe it. So I thought that was very interesting. And it made a lot of sense. And we've all seen like the candy bar, you know, people taking candy bars and using them for for the Bristol stool chart, which maybe, I don't think I'm on board with that because I like a good candy bar...

Amber Tresca 17:08
No, don't touch my Twix.

Amber Tresca 17:16
You know, there's lots of aspects to caring for a person with ulcerative colitis, and lots of aspects to the disease and different symptoms. But I think sometimes patients are not connecting things, or there's things that they don't want to bring to their doctor's. Dr Ha, you already brought up, Like going to the bathroom in the middle of the night? Are there other things that your patients probably don't tell you? Or sometimes don't tell you? But actually like you, you really want to know, and it would help if you knew it?

Dr Christina Ha 17:43
So I think you know, Rasheed had kind of alluded to it earlier, what I find is that, you know, most commonly people downplay their symptoms. And you know, and I think that this is where knowing the people that you take care of helps, and just knowing a little bit more about their story, because now I can get a read. And I can say, Okay, well, you know it, but is this really true? So, you know, are you really only having two bowel movements a day?

Dr Christina Ha 18:07
Then I'll ask, Well, how about how many trips to the bathroom? This is where the question about passing gas without moving your bowels, or passing just blood and mucus comes to play? And then I'll ask, are you able to get through an entire day of work? Can you go shopping? Can you go out with your kids to their soccer meets and not worry about where a restroom is? And then another thing that I'll ask is okay, I know you have some symptoms right now.

Dr Christina Ha 18:30
And you know, although in our scientific medical minds, our goal is we want to heal the colon. And I always explained that, but I also say, let's come up with another personal goal. So within the next hour or so what is important for you to be able to do in three to six months? And you know, what can't you do right now? And oftentimes that will tell us okay, well, I can't go on a hike all day. Well, why can't you go on a hike all day? It's because I have to stop often to use the restroom. Or I'd like to get a good night's sleep well, okay, but why can't you get a good night's sleep? And this helps tease things out.

Dr Christina Ha 19:00
Because I think that we oftentimes need to find more circuitous way sometimes to really get a sense of how often and how significant people's symptoms are. If you just say, Well, you know, how many times to go back to the bathroom during the day? How many times at night? How often do you see bleeding? You know, do your joints hurt? And then you just check mark boxes, and you can say, Oh, you have you only have mild symptoms, you don't need anything else. We don't need to do anymore. And I think that that happens a lot.

Amber Tresca 19:27

Rasheed, when you were talking to your doctors, either in the beginning or even now, is there something that would make you feel more comfortable? You said you were sort of very scientific about it. But I think approaching it from that angle might also leave out sort of the quality of life or the emotional aspects to things. Is there a way that someone could have spoken to you that might have made you elaborate a little bit more?

Rasheed Clarke 19:51
I think just the way that Dr. Hall had framed some questions in terms of day to day activities like can you do this? Can you do that but what's getting in the way of doing those things? And I think for me, the initial consultations with doctors who weren't really necessarily specialists in IBD, or anything gastro related, like things were a little bit tougher than it was very scientific, clinical language when we talked about symptoms.

Rasheed Clarke 20:17
But when I actually eventually got into see a GI, who was terrific, and you know, had a, you know, a much better rapport with him, you know, he was someone who had seen it all could understand what, what kind of symptoms were that I was dealing with, and how they may have impacted day to day life. So when you actually finally meet a doctor who gets it, then it becomes a lot easier to talk about what your day to day life is like, and how it's being inhibited by the disease or by the symptoms, that sort of thing. In terms of other things I could have helped just make things more comfortable looking at how my disease progressed, long term, I would have liked to know a little bit more of a roadmap and knows pretty big ask to say like, no, here's what your future is going to look like with IBD or with with ulcerative colitis.

Rasheed Clarke 21:04
But knowing that, you're going to start with say treatment A and in case that doesn't work, we move to treatment B and then from there to treatment C and then down the line to potentially your ostomy or surgery. So having a little bit more of a long range view for what life with ulcerative colitis, could look like I think that would have made things a little bit more comfortable for me as well, because it was very much focused on that moment that I was in with my medical team, and trying to get things under control at that time. And I kind of lost sight of what things might look like a year from now, five years from now, however, many years beyond that appointment. And I think that's something that may have made things a little bit more comfortable at the time.

Dr Christina Ha 21:46
Rasheed, you bring up such an important point. And this is hopefully the the new wave of how we approach taking care of people with ulcerative colitis is because it's not perfect. And we're always trying to strive for more predictors of progression. But we do know some. And I think it's always very important whenever we're meeting somebody, and we're talking about a treatment strategy to say, Okay, this is why we need to invest in addressing this. Now, because of these features that are present right now, we know that the risks are this. And so but we also know that if we can control it, we can potentially mitigate or decrease the likelihood of these things happening.

Dr Christina Ha 22:24
And by the same token, if we're starting a treatment, we always should say, okay, these are expectations of how this is going to work. This is when it should work. This is our potential adverse effects. And if it doesn't work by time x, then we're going to regroup and come up with a plan B, that is how the conversations should be when we take care of anybody living with inflammatory bowel disease, especially ulcerative colitis. So those points that you're bringing, hopefully, a lot of us in the medical field are now trying to absorb those and change the way that we frame our visits.

[MUSIC: About IBD Transition: Serene]

Amber Tresca 23:03
Dr. Ha, do you have any advice for patients when they're coming in? And they feel as though their symptoms aren't being addressed by their team? Currently, other than getting a second opinion? Or, you know, maybe seeing an IBDologist? How can they get those things addressed?

Dr Christina Ha 23:20
Well, the first is, we need to make sure that you're getting routine follow up. If you're having active symptoms. It's not a strategy where you are given a regimen and then you have your next follow up in three to six months or question mark, you need to have routine follow up, especially if you have activity. I actually think this is a positive of teams where it's also includes advanced practice providers, such as nurse practitioners and PAs. You know, having scheduled check ins, maybe every one to two weeks, two to four weeks with symptom updates is important so that people can assess these trends.

Dr Christina Ha 23:56
And you know, getting your routine lab work. So for example, when I talk to the people I take care of, I tell them, Okay, these are the symptoms that are bothering you right now. So these are the symptoms that I need a symptom update in one to two weeks. So right now, I need you to let me know, even as a simple message, maybe through your EMR or through our API, our advanced practice providers, saying okay, tell me what your store frequency consistency bleeding, the symptoms that were active right now, tell me how they're doing that way. This serves as your symptom diary, and we can follow things over time. So that way when we regroup, I know what's been going on a week to week basis.

Dr Christina Ha 24:32
And you need to know these are the symptoms that we're concerned about. And if you're not experiencing improvement, then we need to do something different. If I start you on a treatment regimen, you need to know how it's worked, and especially for some of the medicines how it's given, because you can't give an enema to somebody and not explain how to use it or suppository or foam because those contractions are foreign. And if you don't explain, then that's not going to work or people may not want to use it. And so I think that really providing in that initial visit, which is going to be more detailed the expectations from both

parties, well, this is what you should be expecting from your provider. And this is what the provider should be expecting from you so that we can work together, because that's what shared care is about.

Amber Tresca 25:14
Right? You know, using enemas way back in the day as part of a colonoscopy prep, I'm trying to remember if anyone actually told me how to use one, or if it was basically just go and buy one and then read the instructions that are in it. Yeah, I really feel like we were kind of on our own.

Dr Christina Ha 25:31
I probably shouldn't. I kind of reenact it, but I also have cartoons, that kind of show involved, you gotta be on your left side, there's got to be a knee band, you got to insert. But if you don't explain, I mean, I don't think I would use unless somebody explained to me why I should be, you know, putting that in a direction that's traditionally unidirectional. And you know, how long we should use it? Do you not? I mean, I mean, it's just a foreign concept, simple things like that somebody needs to teach people how to do this or explain. Right?

Amber Tresca 26:04
I think that's right. And then also feeling as though if you get into a situation where you aren't sure if you're doing it right, or you think you may be actively doing it wrong, that you can come back and say, This is what I did. You know, is it right? Is it wrong? You know, where do we go from here to have that two way street? That's important.

Dr Christina Ha 26:23
But Amber, I also want to mention something that you had alluded to earlier, about, you know, getting a second opinion. And what I would say is, you know, what, if you have a provider who is so cocky to say that they don't need you to get a second opinion, that they're the wrong provider. You know, I take care of people living with Crohn's and Colitis, you know, all day. That's all I do. And I routinely say, you know, what, we may need to look for some more options, why don't we get another opinion, to discuss what the options are, so we can come back to the table, because this is a team sport.

Dr Christina Ha 26:51
It's not in a one on one event, and no person has all the answers. And I think that one of the things, because we do have IBD centers out there, but there may not be directly accessible to everybody is asking for that opinion early so that we can get a roadmap to try something sooner rather than later. So I always encourage getting additional opinions. If you feel like you're stuck.

Amber Tresca 27:15
Yeah. Rasheed, obviously, you know, you had surgery, same as I did for your ulcerative colitis. So how did you know how did you know when something stopped working? Because it can be insidious, I think, and sometimes you don't even really realize what's going on until somebody else looks at you and says, Hey, that's not right. So how did that go for you?

Rasheed Clarke 27:33
Yeah, well, I think before I answer that, I remember looking at the questions that you sent me ahead of time and seeing that question about like, didn't treatment stop working for you, and I didn't treatment stop working for me, of course, it's not working for me. I don't think I would know you if they didn't.

Rasheed Clarke 27:48
But the biggest homework, for me, when I got a sense that the treatment was starting to lose its effects was that the flare ups came back. So normally, one to two trips to the bathroom a day started to turn into fi started to turn into 10 started to turn into 20. So the increase in frequency was a clear indicator, and then the blood would a what if you're in the stool, again, when when I tried to stop doing this thing for me, I had about two years on 5-ASA, that worked really well. And then all of a sudden, like when that stopped working, I could feel the flare ups coming back and other treatments, basically the same course of action. And I would need prednisone to get the flare up under control.

Rasheed Clarke 28:34
And that's typically how things kind of worked for me for several years where I've tried treatment, it would work for a little bit stopped working, going friendzone trying to transition to the next treatment that would stop working, go back to prednisone, and so on and so on. And even eventually, the prednisone stopped having the immediate impact that it once did. And I think I could start on on 40 milligrams a day at the start of a flare up trying to get it under control. Eventually, that had to go up to 60 milligrams a day to get the flare up under control. So things just stopped working as well as they could. And for me, biologics, were there were more biologics on the table, I think when I opted for my surgery compared to possibly when you have yours, Amber...

Amber Tresca 29:17
Yeah, there was zero.

Rasheed Clarke 29:22
A little bit easier for you. I think. There was um, I did, I did try one biologic that worked for about a month before it stopped working. And at that point, I felt like that was the sign for me that maybe surgery was the best option there were there was at least one other biologics approved at the time and I think there were probably others that were very close to being approved. But when when I lasted a month on that treatment, and you know, I went into with it went into it with all kinds of hope and to carry this is the one like I'm gonna finally get things under control and then after a month, it's right back to a flare up.

Rasheed Clarke 29:57
I thought, Okay, at this point, it feels like it Almost an inevitability that surgery is going to come. If it's not now it's going to be after the next failed treatment or the one after that. So it might as well get it done. So every time a treatment started to wane in its effects, I'd see the diarrhea go

up again, I'd see the blood in the stool. Again, it was pretty, it was pretty routine. And a good clear indicator that it was time to move on to the next treatment, or, in my case that the treatment of surgery when when the time came,

Amber Tresca 30:30
The fact that it was pretty routine, and that you knew what was coming. That's just, that's upsetting. That's upsetting because it sounds like you never really got to a place where you were in a sustained remission.

Rasheed Clarke 30:43
It's upsetting. But at the same time, it was helpful in the sense that I knew very clearly like this is not working. And maybe that helped me progress to the next treatment a little bit sooner than if I had just tried to kind of, you know, beat a dead horse with a treatment that obviously wasn't working, but I just really wanted it to work. So just being able to move on to the next thing may have may have been a blessing in disguise, I suppose.

Amber Tresca 31:06
Yeah. Is there anything else that you wish that you had known, you expressed that you wish that you'd had sort of a roadmap, going into your disease and knowing what some of the possible outcomes could be? Is there anything else that would have helped you if you had known it sooner?

Rasheed Clarke 31:21
I think knowing the potential severity of the disease, in a way actually would have been helpful at the start, because I was under the impression after my diagnosis that take some pills, because that was my first prescription with a five AC and take these pills. Everything else in life is normal, and you'll be fine. And that's just your life from here on out. And I thought, okay, like, that's very manageable. That's easy. Like, that's no problem, I can handle that.

Rasheed Clarke 31:48
And no one had really prepared me for what would happen if the treatment failed? Or if like, was there another treatment to take? And would that still keep life relatively simple. I didn't think that it would eventually lead to you know, having to try and die changes different treatments and have to consider what kind of work I did where I do my work, because I want to stay close to better medical professionals or hospitals if I need to. So there was a lot that was left unsaid when when I was first diagnosed.

Rasheed Clarke 32:19
And I'm one that likes to at least know what could happen to me rather than you know, put my fingers in my ears to say like, no, no, nothing bad's gonna happen. Everything's gonna be great, I'll take these pills, everything will be fine. Just knowing what could have been in store I think would have braced me a little bit more because when things did go wrong, and they did go wrong, I think it hit me a lot harder than if I had some sort of feeling that this might be a possibility. Because it felt like maybe I was either not doing things well enough myself or the

simple treatment that wasn't working for me made me feel as though I had like a really bad if I guess I did have a pretty bad taste of ulcerative colitis, obviously, but I always have a feeling at the start when I was first diagnosed, that this was going to be relatively easy to manage and it turned out to not be

Dr Christina Ha 33:10
well received, you bring up such an important aspect of how I should think about the experience of the people living with ulcerative colitis because, you know, one of the struggles is you know, it's it's easy for me to say okay, you need to be on treatment X y&z Because those are tangible items that I can prescribe. But you know, what I will say is a lot of people's journey with ulcerative colitis is very challenging. And it's fraught with a lot of ups and downs. And, you know, I always try to say, Okay, let's there's room for optimism, you know, let's let's do this. And then let's see, but I know I can see how much of an emotional and psychological toll it takes to just go after one medication after another or go on another course of steroids. So just curiosity, you know, how can people like myself help and be better?

Rasheed Clarke 33:58
Giving instructions on how to give an enema I mean, like, that's, I've never heard that before. But just having a realistic outlook on things, it's important to have that room for optimism, certainly, I think that's vital. He can to tell people like, well, you have this disease now. Everything's gonna be terrible. So let's brace yourself for that. Like, we don't want to have that kind of message either.

Rasheed Clarke 34:19
But having a realistic understanding of what could happen, and knowing that there are contingencies, I think that is the key for me is not just saying, okay, these bad things could happen. And then we'll see what happens then. But knowing these bad things could happen. And if they do, we can treat it with XYZ, whatever it may be. It's interesting, I say zed as opposed to Z, I don't know if you picked up on that...

Dr Christina Ha 34:44
It automatically sounds more fancy.

Rasheed Clarke 34:50
The actual letter, not the sound that you're making. But having those contingencies, I think would be something that would be very helpful to know that these potentially adverse offence could happen, but if they do we have we have plans in place that could potentially treat that rather than just the like, here's this treatment now, on your way everything will be fine.

Amber Tresca 35:25
Rasheed, do you have any fun or embarrassing stories to tell about your ulcerative colitis?

Rasheed Clarke 35:32

Of course I do. There's tons of embarrassing stories that in fall of 2011, I was coming out of a flare up, or at least I was on prednisone to come out of a flare up and things were starting to the meditation was starting to help at the time. So the number of trips to the bathroom per day was starting to come down. And you know, life is becoming a little bit more manageable, to the point where I thought, Okay, I'm in good enough shape to go running again.

Rasheed Clarke 36:01
And you know, I haven't done in a while so it'll be good for me, I'll get out and and meditation is working, so I'll be fine. And maybe one kilometer into the run, of course, felt like I had to go and couldn't hold it in. So I'm trying to slow down and trying to hold it in, nothing's working. And things start making their way out.

Rasheed Clarke 36:23
And so I happen to be in a place where there was a wooded area just off to the side of the road where I was running, so I ran into the wooded area. At that point, lots of stuff had come out. And I used clumps of leaves to try to clean things up as best as I could, in that wooded area also to take you know, cover from other people who may be in the general vicinity. So what I was using leaves as my toilet paper to try to clean things up as best as I could.

Rasheed Clarke 36:53
And that was the point where I felt like okay, now I'm ready to go face the world again, but just enough to clean up the mess and get myself to the point where I can be comfortable enough to walk that kilometer back home. So that was that was the run and and leaves in the wooded area. embarrassing story.

Dr Christina Ha 37:12
Oh, I thought you were gonna say it was poison ivy. Oh my god.

Rasheed Clarke 37:21
And it's funny because now I'm thinking back to that time and I wasn't even really thinking about what kind of leaves to use. I'm just thinking like, what's like dry and big enough to like form something that would be you know, good as a toilet paper substitute. Luckily, nothing worse from from my foray into into the woods that day. Other than other than filling embarrassment, which obviously isn't as bad now because I'm I'm openly talking about it, which is probably a good sign.

Amber Tresca 37:48
Also, I was waiting for you to say that it was the run with the runs.

Rasheed Clarke 37:55
I mean, that was too obvious. One, like, get to the bottom of it. Yeah, overload this episode with Oh,

Amber Tresca 38:07

Come on, you know me. So Dr Ha, I, in doing the research prior to this episode, I discovered something that I didn't know about you. And I was horrified to learn that I didn't know this about you. But you did Jimmy Kimmel's colonoscopy in 2018. And I did not know.

Dr Christina Ha 38:30
Yeah, yeah, he chugged that bowel prep, like you're not supposed. Just down the bowel prep, I thought, Oh, he is not gonna appreciate what he just did in two hours.

Amber Tresca 38:46
So Well, tell me about that, though. Like, is there anything that you can share from that? And how did you know? Were you there with him during the prep as well? I mean, that's some really like, you know, red carpet treatment, if that's true.

Dr Christina Ha 38:59
Well, so it was all part of a an event for Stand Up to Cancer, which is foundation that was started by Katie Couric and marches colorectal cancer awareness month, and I got a phone call from one of my colleagues, Dr. Mark Pochapin, who's at NYU, who is very involved with Stand Up to Cancer. And he said, Oh, you know, I have a fun little activity for you to do and I thought, okay, you know, I'm not gonna say no to you, and fun is fun.

Dr Christina Ha 39:27
And he said, How would you like to scope Jimmy Kimmel? I thought, that's fine, you know. And then, and so I actually was not aware of how much of a production this was going to be, until I showed up around five in the morning, and they had me do all this sticky stuff, like, play an operation game and I arrived to my scrubs. I woke up. I didn't have my Starbucks yet, so I might have been a little grumpy.

Dr Christina Ha 39:55
The funny part about it is they said, Okay, we're gonna let you you know, get ready and I thought Myself, yeah, this this is what you're getting. But, I mean, I thought it was, it was a really a great thing for him to do because he had filmed the night before. And he had this bit with Katie Couric. That's where he drank the bowel prep. And he got up early. And you know, I was really worried that he wasn't going to be clean. So he was perfectly clean.

Dr Christina Ha 40:26
And it's, you know, I have to say, it's tough to be that schtick-y at like five in the morning, but he did a great job. They brought him balloons, and I thought it was a really great opportunity and to bring awareness to colon cancer, and he was he was a lot of fun. Next time, I know that when you get a call about doing something on a celebrity for colon cancer, that maybe they expect you to put on some makeup and to fix your hair. But it was great. And it was a nice experience. Definitely something different from my day job. You know, I was most disappointed that I didn't get to meet Guillermo, you know, Kimmel's. I was also worried that he was going to drink Kimmel's bowel prep too, because. Right. But yeah, that's that's how that came about.

Amber Tresca 41:19
I can't believe I didn't know. I can't believe you don't introduce yourself to people that way. Hi, my name is Dr. Ha, and I did Jimmy Kimmel's colonoscopy, but it was interesting, I think it was, you know, watching the clip, his his bowel was really clean.

Dr Christina Ha 41:34
It was super clean.

Amber Tresca 41:36
I mean, not only that, but like he was so witty, after waking up from that nap, what I usually call the propofol nap, I like, I would never allow anyone to film me after that. And so it was incredible.

Amber Tresca 41:52
I'm old enough to have remembered when Katie Couric's husband died of colon cancer. And then she became a crusader for that. And the Katie Couric effect and how many people got screened after she herself got screened on the Today's show. I was big fan back in, back in the day, watched it every morning before I went to work. So it was fantastic to see that to watch that. I'm sorry, I didn't know about it before just a few days ago, but I'm glad I got to be to about it. Because I think that's really important and good for you.

[MUSIC: IBD Dance Party]

Amber Tresca 42:21
And you looked beautiful. I mean, it's you know, I mean, you know that you're smart and amazing. And you know, we love you for all of that. But you did you look beautiful, and they whipped out that operation game. And I'll put the link in the show notes for people to watch the clip themselves. But they whipped out that operation game and I was like what the hell is going on?

Dr Christina Ha 42:43
I was so worried about people were gonna criticize my technique. I can hear my colleagues saying "find the lumen."

Dr Christina Ha 42:56
Are my ergonomics correct? But yeah.

Amber Tresca 42:58
Oh, my goodness, well, you dealt with it exceptionally well. So I think that's amazing. And everybody needs to watch it.

Amber Tresca 43:05
Thank you both so much for coming on About IBD. I knew this would be a fantastic episode, because I know both of you and how you are and discussing sharts is like totally at first for this

show. But I think it won't be the last time. So thank you both for your time and for everything that you do for patients with IBD. I really appreciate it.

Dr Christina Ha 43:25
Thank you so much for having us.

Rasheed Clarke 43:27
Always happy to be here. Thank you so much, Amber.

Amber Tresca 43:35
Hey super listener! Thanks to Dr Christina Ha for bringing her knowledge and perspective to this topic and for being an amazing IBDologist and collaborator. Thank you also to Rasheed Clarke for being so insightful and for sharing an embarrassing ulcerative story that many of us can relate to. And on a personal note, thanks for always answering my texts.

Amber Tresca 43:57
Links to a written transcript, social media handles, more information on the topics we discussed, and the video of Dr Ha giving a colonoscopy to Jimmy Kimmel is in the show notes and on my Episode 107 page on AboutIBD.com. You can also follow me across all social media as AboutIBD.

Amber Tresca 44:19
Thanks for listening, and remember, until next time, I want you to know more about IBD.

Amber Tresca 44:26
This American Gastroenterological Association Colitis Conversations program was supported by Pfizer, Inc.

Amber Tresca 44:33
About IBD is a production of Mal and Tal Enterprises. It is written, produced and directed by me, Amber Tresca.

Amber Tresca 44:41
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Amber Tresca 44:43
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