

About IBD Podcast Episode 83: The Streamers From Gaming4Guts

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.

Welcome to Episode 83. My guests are Kenzie, John, and Mark from Gaming4Guts. Gaming4Guts is an online gaming community that also raises awareness and funds for the Crohn's & Colitis Foundation. Every year during Crohn's and Colitis Awareness Week in December, they run a gaming marathon on Twitch.

Twitch is a live streaming service for gamers and other broadcasters. During the Gaming4Guts marathon, community members and others can play with the streamers or even run a stream in support of the fundraiser themselves.

But as John, Kenzie, and Mark will tell you, Gaming4Guts has a reach that goes far beyond a once-a-year fundraiser. It has become close-knit community of people whose lives are touched by IBD. They connect on Twitch as well as on the Gaming4Guts Discord server, which is a messaging platform that is primarily used by online gamers. Don't worry, I will put all this information in the show notes so that you can learn more and connect with them.

Everyone involved in Gaming4Guts has a personal connection to IBD which spurs their interest in raising awareness of these diseases and in helping to make sure that young people don't feel isolated because of their illness.

Hey, Mackenzie, how's it going today?

Mackenzie 1:37

Hey, Amber, I'm doing good. How are you?

Amber Tresca 1:39

And we also have mark, how are you doing, Mark?

Mark 1:42

Ah, you know, I'd be a lot better if I hadn't got off work at three in the morning and just woken up at nine. But things are pretty good.

Amber Tresca 1:50

Alright, we can manage. And john?

John 1:54

I'm doing well. Thank you for having us on.

Amber Tresca 1:56

I'm so glad to talk to you all. It's been quite a few years that I've been following your journey. And so I wonder at first you each Tell me a little bit about yourselves, and a little bit about your IBD journey. And since there are three of you, you know, I think we should just always start with Mackenzie so let's just start with Mackenzie.

Mackenzie 2:15

Hey, everyone, I'm Mackenzie. Um, I was diagnosed officially with inflammatory bowel disease in 2013. But the diagnostic journey kind of started in 2011. I was originally diagnosed with a mildly chronically inflamed rectum by my general practitioner, which, you know, after I learned about inflammatory bowel disease, I'm like Oh, wait, that's what that was. So I went undiagnosed and like, you know, really untreated for almost three years, which is a bit rough, made college pretty rough. Because I experienced flares and college and I, you know, you're "Oh, well this is just my life. Now this is apparently normal for my condition." And you know, I didn't really do a whole lot of research or anything on it. After I got diagnosed, I did realize that I had bowel problems my whole life. You know, could I've been diagnosed sooner, I definitely feel that and I should have went in got a second opinion went into GI and stuff, but I just I just didn't. I was in college trying to focus on college getting through school. So that was, that was my life. And I felt like that was my life until things start getting worse again after I was an adult, finally got diagnosed. We started with indeterminate colitis for my diagnostic diagnosis. But since there's like no really official, you know, diagnostic code for indeterminate colitis on paper ulcerative also have colitis, but we're still not 100% sure if that's what it is, but we're going with it. And I've been on humera for I think seven years, six or seven years this year. And it's been working pretty good. I have breakthrough flares, everyone smile, but for the most part, I am, it's pretty controlled, except for you know, the days that my stomach's upset because it's something I ate. But because I have IBS on top of the, you know, inflammatory bowel disease. So, one things acting up another might be acting up. So sometimes I think I'm flaring, but it's actually the IBS. So I've had scopes to see what's going on. Oh, wait, it's your IBS acting up. Okay, well, I feel better, but at the same time, I'm still not feeling well. So it's, it's all over the place, some days, but for the most part, I'm doing good.

Amber Tresca 4:18

That's so good to hear. And so what strikes me about your story is this idea that you had an inflamed rectum. And they were just like, "Oh, this is just like, this is fine. This is all fine."

Mackenzie 4:28

Oh, yeah. Like they're like, "Well, you might want to go see a GI," maybe not because it wasn't even a GI who did my colonoscopy was a general surgeon. Like did my scope. They're like, "Oh, well, there's some inflammation" and I'm okay. And then my grandmother had all stripped colitis. But, you know, it wasn't something we really talked about as a family. Because she had it you know, when she was younger, and it took a long time to get everything figured out. It was such a struggle for a long time.

Amber Tresca 4:56

I hate to hear that, especially in people that have been diagnosed more recently because it seems like we should be further along than that. Like, you know, you shouldn't have been suffering as long as you have. But thank you for your story. I'm glad to hear that you're doing relatively well. In IBD adjusted terms, we should say, John, what is your connection to IBD?

John 5:15

Well, I'm kind of the outlier of the group and that I myself, don't have IBD. Both of my stepsons have Crohn's, the oldest boy was diagnosed at age five, and the youngest one was diagnosed at age 10. The oldest one is 18 now, so I think next month, is the anniversary of when he got diagnosed. I'd never heard of Crohn's disease before that. I know he's been having, you know, complaining of stomach problems and not wanting to eat and you just think, Okay, well, you're a kid. And you're saying, you've got to go to the bathroom when you're just trying to get out of half and a half supper right now, and you don't really think about it, but you know, things progress. And then "Okay, well, let's go have you checked out" and then he had his first colonoscopy, you know, age five. And the doctor came back and was like, "Yeah, it's Crohn's." And we're very blessed to live. Where we do right now, because the local doctor was not impressing us at all. He basically had a foot out the door, as he's telling us, "okay, he's got Crohn's disease." We're like, "Well, what does that mean? We, we don't know what this is." And it just almost seemed like it was a problem for him to even tell us, like, to go any further into the diagnosis and what we need to do from now on, but we're lucky that we live close to Texas Children's Hospital in Houston. Because they've been fantastic over there. The oldest boy, he's really had some struggles over the years, there was a while where everything he ate was, was not agreeing with him, they were debating on putting an ostomy bag on him and just see if that can help his, his guts heal. And so for a while they fed them through a tube through his nose, to see if that got everything settled down. And it did. And then he got fistulas. And that's, you know, horrible thing for a kid to have to go through. The last big thing that he had to go through was, a few years ago, he got a sinus infection. Well, because he's on his immunosuppressive drugs, it spread through the back of his skull and got into his brain. And they, there's a term for it. Now I'm trying to remember if Pott's puffy tumor is what it turned into. So he had to have brain surgery a few years ago to take care of it. And luckily, like when we went in to go have this done, you know, we're asking the doctors, because we've never heard of this. And there's like, some superstar surgeon over there. And he was like, "Oh, we do these, you know, couple times a month." You know, we're like, "Oh, wow, this, [we've] never heard of this thing. Fantastic." So, you know, he goes in, has a surgery, comes out fine, you would never know now that anything was wrong. And since then, he's been pretty good. With not having a little big, big flare ups, you know, no big issues. And, you know, so that we're very thankful for that. The youngest one got diagnosed, and every now and then his stomach is upset. And it's just a real kind of eye opener to see how differently the same disease can affect people completely different. You know, he hasn't had the health problems that his older brother has, but you know, every now and then, yeah, he's got an upset stomach and got to make sure he's taking his meds and all that. But overall, like with him, you would never know that he's ever had any issues. But the

one good thing about his brother having the surgery, we have at least distinctive scientific proof that one of us in the family has a brain. So...

All 9:17

laughing

Amber Tresca 9:22

I love that. And I love your outlook on it as well, because seeing your kids be sick is one of the worst things ever.

John 9:31

It's hard. It's really hard.

Amber Tresca 9:34

Yeah. And especially with something as complicated as IBD and you had no idea what was going on in the beginning, and you're just you're learning on the job.

John 9:43

Yeah, that's that's exactly it. You know, and we've been very lucky and very thankful that as bad things have been they haven't been worse. That's, you know, kind of the, the outlook I tried to keep with everything, is, you know, Hey, you know what in the situation is bad, but it could probably be worse in some ways. So, I always see the silver lining in that.

Amber Tresca 10:03

Yeah, I agree. I think it helps sometimes to think of it that way. Thank you for sharing that story, wow. Mark, why don't you tell me a little bit about yourself? What's your journey been like so far?

Mark 10:12

Man, first of all, I had to like mute my mic there for a moment cuz I like cried a little bit when John was talking about his eldest son's case with this because there's, there's some massive parallels. I was diagnosed freshman year of high school, which was, you know, a whopping 13 years ago. But I've been showing symptoms probably since about 1998. Middle school was just abismal for me, and I was having blockages, bouts of chronic diarrhea, then like constipation from the blockages where I wouldn't go to the bathroom for like, two weeks, it was really, really rough. And I lost like 30 pounds in like two months, my freshman year of high school, it caused me to drop out, I developed parry rectal fistulas that needed three surgeries to correct to that year alone. It wasn't until after the very first surgery for that that my surgeon screamed and yell that at the gastroenterologist in the little mountain town in southern Oregon I lived in to actually do a colonoscopy because a surgeon was screaming on the phone, "you are killing this child." And he didn't even leave the room that I was in with my parents. He just was like, bring me a phone now. So I thank my general surgeon who did that for saving my life literally because, you know, the parry rectal fistula become necrotic which is why took three surgeries. They put me on it the time, which I'm still on it. And I've yet to find

anyone else who's been on Remicade as long as me but that's what they put me on. Gotta say, it keeps me insanely healthy. I'm able to hold a job, you know, I work 10-12 hour days and have a successful career. I went to college for about nine years in Tennessee. The the hard spots are every once in a while the symptoms flare back up. And what's weird is it's not physical stress for me that really causes any of my symptoms of flare, it's like emotional stress, I go through a really harrowing time, loss of a family member, things of that nature, my symptoms come back in full force. So if I could say anything to people, like freshly diagnosed or going through symptoms is like, you have to learn the art of zen, a lot. Like you have to find a place where you can focus in remind yourself where the ground is. Because without that, like you can get lost pretty quick, at least in my case.

Amber Tresca 13:22

Let's talk about Gaming4Guts. So tell me, what is Gaming4Guts?

Mark 13:27

Not, not to like steal, steal the beginning of this. But that's a lot of things to a lot of people. So you mentioned how people are being diagnosed like younger and younger with Crohn's disease. We have a lot of very young members in our group and have been following us almost since we started. And so for them, it's like a community of people we talk to every day. And it gives everyone a like safe place to come and talk about their disability and their disorder and find those who like to play video games and be able to reach out in have connection with other people. Because I know for me growing up with Crohn's disease. I lost all my friends, no one wanted to hang out with a sick kid. And let's be real children in high school are fickle beings. And so I remember what that's like. And so I like being able to have this networked community for all of the kids and like even people who are adults who are going through this for the very first time in their life, who have no understanding to be able to come together and seek help have questions. For me. It's really kind of a family thing because our founder Brad Watson and our other founder Rob, I've known them for an incredibly long time. And our founder Brad he is like a brother to me. He lives, unfortunately, he lives up in Canada, but when I moved back to This side of the country, like he drove down from Canada, and we got to hang out for the very first time. And it was really like fun and emotional. And we had a blast. And so, like, for me, it's like that real connection finally coming together. And it's been able to do that for us, so...

Amber Tresca 15:18

And tell me how you're connecting with folks.

Mackenzie 15:21

It's mostly through the Discord right now, I believe. Because people post on there, like when they start live streaming on Twitch, so you can go hang out and talk to people while they're streaming and playing video games. And then we have different channels in there that different subjects, so people can go in there and say, Hey, I'm in a flare right now. Like I'm having a rough time. And we'll always have well, that really sucks. And we can talk to them about it and what they're going through. And sometimes, like

we talked about hobbies or post pictures, like, "Hey, I baked bread today, because me and Mark have done that a couple of times, we're like, hey, look at what I made."

Mark 15:51

Yeah, we've done that a lot.

Mackenzie 15:54

Uh huh. And it's just really cool to be able to talk to people in there. And this year, especially, it's been so nice to have that group of people to interact with just because of COVID. You know, a lot of us are stuck at home, we're not really going out and unable to see friends. But your online friends, they're always there for you- well maybe, the most part, they're always there for you. Like everyone may not be online at the same time. But we have people all over the world in this Discord. We have people from Europe in there, we have people from all over the United States in there. And, you know, it's just almost like a big instant, instant messaging forum. So you can talk to people from all over the place and be able to interact with somebody and have online friends who you can go interact with talk with play video games with, you know, because a lot of us are stuck at home even before COVID you may be stuck at home and a flare that turns into like some of your best friends in the online community. You know, they're there for you, especially after you get diagnosed, you can feel so alone because I know I did after I got diagnosed, and that's one thing I love about Gaming4Guts is I have these guys to talk to and interact with, then someone who can relate to what I'm going through. And it's been such a big help. Over the years.

Amber Tresca 17:04

You talked a little bit about your founders, where did it really begin? It started with a Discord server, right?

Mark 17:10

I don't even think Discord had been invented yet.

John 17:12

No, no, because that would have been, I think the first was in 2014. And Brad and Robin known each other through different gaming channels like they gamed online together. And they said, Hey, we should do a 24 hour stream. And we'll do it for the Crohn's and Colitis Foundation. They came up with the event. And where I come into, into the picture is in April of 2015, I did a 24 hour charity stream for Crohn's and Colitis Foundation, not knowing that there'd already been another one. And so I got introduced to a lady named Jessica that worked for Crohn's and Colitis foundation. And then she got me in touch with Rob. These guys have already done it, you should talk to them about you know, if you have any questions. And so I got in contact with Rob and he just kind of gave me some pointers, because this was the first time I was ever going to do any kind of streaming at all. And it just kind of came from this desire of like, you know, can I play video games for 24 hours? You know, and how many video games can I beat in 24 hours? Did that I thought it was going to be a one and done thing. A couple months later, Jessica gets in contact with me and says, "Hey, the guys that did this

event before they're getting ready to do another one in December again, would you be interested in joining them?" And I was like, "Well, sure." You know, because I really hadn't really thought about it. And so you know, we got together. And so 2015 for the second Gaming4Guts group. I think that was the first time we really had like any kind of widespread participants, because before it just had been Brad and Rob, then Mark is that year that you joined or was the year following that?

Mark 19:04

I didn't stream on year one, but I did play on the video games with them all 24 hours. And then the second year. I tried to stream but I had like equipment malfunctions, all 24 hours. So people were just staring at my webcam and a black screen. The video games were not loading for me, it was a catastrophe. It was sad. So it's really year three, that is where I came in. And I brought a gaming group that I play with, who are all just big supporters and because they're my friends, they came along, um, you're gonna have to probably bleep this one, but that gaming group is called the Fuck Ups.

All 19:43

laughing

Mark 19:46

And, I brought them along and now every year, at least two of those guys join me and even if they can't stream, dude, they're like work constraints. They have streamed in the past, but if they can't stream they still play with me. So they're frequent on my stream, you'll hear like, Don's voice or Ryan, or Jared, they'll all just be talking and then becomes a cacophony of sound and you have no idea what's going on. It's great.

John 20:13

And you're their leader.

Mark 20:14

Yeah. Which is the sad thing.

Amber Tresca 20:19

So does everybody do a 24 hour gaming stream? Or how does that work?

Mackenzie 20:23

It varies. Some people do the 24 hours, my body just can't handle it anymore.

Amber Tresca 20:28

I can't imagine it.

Mackenzie 20:29

I have found with my inflammatory bowel disease, if I'm up for 24 hours, four or 5am, because I normally start at 8am, four or 5am. I'm going to the bathroom every 20 minutes. And it's exhausting. So I'm like, you know what, I'll stream for 12 or 16 hours, like everyday by at least have to go take a break and go to sleep?

John 20:46

Yeah, I'm kind of the same way. But it's more due to my advanced age than anything else.

Amber Tresca 20:51

But you don't, you don't have IBD, what's your excuse?

John 20:55

I'm old, I got to make sure there aren't any kids on my front lawn.

Mark 21:02

Yeah, that is the going joke. He's the old man. And there's always children on the lawn.

John 21:06

Yeah I gotta kick it off. So so like, what I've started to do is, you know, because we've expanded from being just a 24 hour stream to basically doing the whole weekend, as I'll do. Like, in the past, I've done like 3 12 hour streams, you know, this year, it might be like, eight or 10 hour streams and all that I'll end up doing. But last year, Mark, didn't you do like 984 hours or something like that it was, you were just on all.

Mark 21:36

So, um, the last two events. And now going into this one, we have done a 72 hour full weekend. So there's this constant evolution, right, it starts as just a 24 hour, then it became 48. And now it's a 72 hour like death fest. And the last two years, I I pushed my body to the limit, I think one year I streamed continuously for like 59 hours. And then last year, I did like 62. And I was a zombie, I was just like nope, none of this.

Amber Tresca 22:20

Is that the longest, you think? 62 hour?,

Mark 22:23

That's the longest I've been able to keep it up.

Amber Tresca 22:26

So does it get more entertaining over time? So, if I tuned in to watch that I watch you at hour 20, 30? That'll be better than hour one?

Mackenzie 22:36

Ah, some of us getting a little slap happy, you know, when it's like four or five 6am. Like towards the end of the 24 hours. Like, you're sometimes you're just so frustrated at that point with whatever game you're playing it and then like, I've like started like fall asleep, like while I'm playing and I'm like, Oh my god, like I got to stay awake and it gets rough. And some of us just get a little a little loopy, you know, towards the end of the stream.

Amber Tresca 23:09

This is all to raise money for the Crohn's and colitis foundation. Well, it's not all for that. It's mostly for that. It's also for fun, too, obviously. But I would really like to know from each of you why it's important that you raise money for the foundation in this way.

John 23:23

For me, I think that this is a like we've kind of been talking about this is a great way for people with IBD to be able to participate in a fundraising event that they normally wouldn't be able to otherwise, this is the kind of event where you can do it in the comfort of your own home. If you need to go take a bathroom break, you can you know, hit pause put a "Be Right Back" on the screen and go do what you need to do. And people understand that they know that, especially if they realize that you're sick, and you've got reasons that you need to go take care of business. That's fine. And, you know, because there's so many, like we've been talking about, you know, more kids being diagnosed, this is an event they can get behind, this as an event they can want to do. And, like for me, like that's one of the biggest things is you know, to me, it's like the more eyes we can get on this, the more money we can raise for the foundation, you know, the more support we get back.

Mackenzie 24:25

Raising money to help you know get the word out there about inflammatory bowel disease because it affects so many people and you know, it's not just a bathroom disease, there's so many other things that affect it like like when John's stepson. Like, I didn't know that that could happen like, you know, that, that's crazy that you know, he ended up getting that severe brain infection that he had had brain surgery from medications on first Crohn's disease because so many, so many people out there like well you just go to the bathroom, and it's just so much more than that. And this is a great way to get the word out and a great way to raise money for you know, educating people in you know, trying to find a cure for this.

Mark 25:05

I am the third person in my family to be diagnosed with Crohn's disease and the only one that is a male. My aunt, she had it. I watched her funeral when I was four years old. She died from Crohn's disease. My great aunt also had it, and she died from complications in her... like, I think she was 81 years old. This was a couple of years back. And very, very personal, real connection to that. And when they were young, the medications that we have now definitely don't exist. I mean, two of the most commonly used ones now didn't exist. When I was first diagnosed, we had steroids in Remicade, all they had were steroids. For me, bringing that awareness out there. That's really why I'm in this because I had to suffer. I've had family members suffer from it. I don't want other people to suffer, like they need to know what the symptoms are to get things checked. Yeah, the doctor bill's sucks, getting a camera shoved up there, is not the most pleasant experience in life. But if it saves you from a lifetime of suffering, like, it's worth it. So, it's really about awareness. And that's why I'm in this. It's a very personal connection. It's also a way for I think, some of us to heal from the emotional trauma we've suffered because of this.

Mackenzie 26:43
Mm hmm.

Mark 26:43
And that's really why I'm here, and why I will stay up for 62 hours playing video games

Amber Tresca 26:51
That's a good reason, I think.

Mark 26:53
Yeah.

Amber Tresca 26:54
So tell me, this year, what are the dates for Gaming4Guts?

John 26:58
Gaming4Guts is December fourth, fifth and sixth this year, I historically have kind of kicked off the event. But I know there have been other times when someone's started streaming earlier than I have. I usually starts around noon central time.

Amber Tresca 27:14
So how can folks get involved with gaming? Where can they go?

Mackenzie 27:18
We're on Facebook, Twitter, Instagram. Facebook and Twitter can be the best place to find the link for Discord. And we're mostly in Discord at this point. And then we're also the main Gaming4Guts twitch page is also on Twitch. And then a lot of our streams are linked to that page too. So you can go to there and see who in the community is live.

Amber Tresca 27:41
Well, thanks, guys. This was fantastic. I'm so happy to be able to see you and talk with all of you since I've been following you all for years, of course, and following Gaming4Guts. And I'm really looking forward to the stream this year and looking forward to see what shenanigans are getting up to.

John 27:56
Thanks for having us.

Mackenzie 27:57
Yes, thank you, Amber.

Mark 27:59
Thank you. It's been a wonderful time.

Amber Tresca 28:05

Hey, super listener! Special thanks to Kenzie, John, and Mark for sharing their stories and for all the work they do in raising funds and creating a community for people with IBD.

You can become a part of Gaming4Guts. You can not only join the community on the Discord server, but you can also stream or play during the event. For 2020, the Gaming4Guts live stream will be from Friday, December 4th through Sunday, December 6th.

I also want to call your attention to the fundraising milestones this year. If Gaming4Guts raises two thousand five hundred dollars, Kenzie will take a whipped cream pie to the face. At five thousand, Kenzie will stream in a T-rex costume (and I can confirm she already has the costume). At seven thousand five hundred, Kenzie's husband will do her makeup on a live stream. And at ten thousand, the admin group will stream a sing along. No word on the song but maybe we can make some suggestions?

The Gaming4Guts, and that is gaming, the number 4, guts, information is the in show notes and on the episode 83 page on my web site aboutIBD.com. I am in the Gaming4Guts Discord server as well as all over social media as @aboutIBD.

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

About IBD is a production of Mal and Tal Enterprises.

It is written, produced and directed by me, Amber Tresca.

Mix and sound design is by Mac Cooney.

Theme music is from Cooney Studio.

Amber Tresca

Anything to declare, as they say, when you're going over the border?

John 29:51

Uh, my pocket knife is not a weapon and, uh... I have no tobacco or alcohol on me. So this is in the outtakes, right?