

About IBD Podcast Episode 91 - Derek Mari of Crohnie: It's Not Impossible

Amber Tresca 0:04

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 91. It is my pleasure to introduce you to Derek Mari. Derek lives with Crohn's disease by way of a long diagnostic process that included an initial misdiagnosis of ulcerative colitis. Derek is an actor, writer, and filmmaker. His IBD journey has inspired him to create a story that explores the way people cope with living with a chronic illness.

On this episode, he's going to tell you about his life with IBD and how it has impacted his chosen career path in entertainment. We also discuss the short film Derek made called Crohnie. And here's the best part: the short film is only one scene from Derek's full-length movie script.

Derek's next goal is to film a full-length feature movie from his script, which follows a character who lives with Crohn's disease and explores how he copes with chronic illness. He will tell you how he has integrated his IBD into his work, why he was compelled to tell this story, and how you can get involved.

Amber Tresca 1:20

Derek, thank you so much for coming on About IBD

Derek Mari 1:23

Thank you so much for having me. I'm really excited to be here.

Amber Tresca 1:25

Oh, I'm super excited. I have so many questions for you. A couple of them have to do with your IBD journey. But I have to be honest, most of them have nothing to do with your IBD journey.

Derek Mari 1:34

Amazing. All the above.

Amber Tresca 1:37

Okay, great. But first, let's just get a level set. And let's talk about your actual diagnosis journey and how you got to a diagnosis. And you know, what kind of bumps happened along the way what kind of things happened?

Derek Mari 1:50

Yeah, no, that's a good question. I want to say first off, usually with like, recording podcasts or any types of videos, I'm sometimes nervous about my stomach making a sound and creeping

into the audio, but I feel very comfortable here. I feel like it's almost encouraged. Thank you for creating that space. Yeah, so I am 25 years old. I live in Los Angeles. I was diagnosed with ulcerative colitis when I was 15. I was growing up in Modesto, California, which is a small agricultural town in the Central Valley of California, and had a solid year of like, pain and symptoms and going to different doctors and wasn't finding the right doctor, there weren't enough doctors specializing in IBD or ulcerative colitis, Crohn's specifically. And so I was on a lot of like topical medicines, or oral medicines rather. And yeah, trying to figure out really what was going on with my body.

But it wasn't until I was 18 when I moved down south to Los Angeles started going to film school in LA, and I started going to UCLA health. And there started going to a gastroenterologist who diagnosed me with Crohn's instead of ulcerative colitis, and kind of like filled me in on like the neglect that I had been experiencing, like I had, my symptoms had flared. And I had gotten progressively worse, unfortunately. And I started going on, I guess, after a year of then trying all these different medicines, which is also during my first year of college, which is like, you know, not the most glamorous disease when you're a freshman in college. Eventually started going on Remicade, which is like a six week infusion. And since then, I've really gotten my symptoms under control. And I've been in remission for almost two years now.

Amber Tresca 3:55

So was pain, the biggest symptom that you had really in the beginning?

Derek Mari 3:59

Yeah, yeah, definitely, like the very beginning like 1415 years old, just having stomach pain and cramps. 24. Seven, and, you know, kind of like, a lot of it was connected to anxiety and puberty and like, what is going on with my body? And then not Are we allowed to get graphic on this podcast? Great. I hope this reaches the world. Then when the stool started getting bloody, then we're like, oh, something's going on internally, and this is this needs to be taken care of. That's when I started seeing a doctor and and start getting on medicine.

Amber Tresca 4:41

How did they diagnose you? Did they do a colonoscopy?

Derek Mari 4:44

Yeah, they look at Yeah, colonoscopy. Yeah.

Amber Tresca 4:47

And that's when they that's when I told you ulcerative colitis.

Derek Mari 4:49

Yes, yes.

Amber Tresca 4:50

So then when you started seeing a different physician who was I don't know, maybe this is fair to say maybe a little more competent or a little more educated about IBD? Yeah, what Did they do that then changed your diagnosis?

Derek Mari 5:03

also did a colonoscopy? Yeah, I think I think also, you know, I don't actually know I'm trying to edge educate myself about IBD and the spectrum of ulcerative colitis, and Crohn's and all of the above. I'm still on that journey to learning more about it. But I think, I think my symptoms had just gotten worse. And my disease had gotten worse over the years. So that when I did get that colonoscopy, almost four or five years later, there were there was more damage. And there were more flares, I suppose. So yeah, by then he was like, this is kind of severe. We're gonna label it as Crohn's. And we're gonna put you on some new medicine.

Amber Tresca 5:46

This is kind of severe. Not what I imagine you want to hear.

Derek Mari 5:49

I'm like, great. What have I been doing for the past five years?

Amber Tresca 5:53

Exactly. Well, getting worse, apparently. Yeah, very unfortunately. So you were in college, and all of this is going on. But you're now a filmmaker, you're a director. You're also a writer, amongst many other things, actor as well.

Derek Mari 6:12

Wow. Thank you.

Amber Tresca 6:15

So but here's my question, though. Somebody who has IBD, who is going to go into the entertainment into any of these professions. Like that's, that's a difficult prospect. Did you ever have anybody sort of pull you aside and say, I don't know about this for you.

Derek Mari 6:34

You know, the film industry is so difficult in so many different ways. It's mentally taxing, as well as physically laborious. And yeah, having a autoimmune disease in the film industry, it's really, really hard to navigate that. Because starting out, I just wanted to be on set as much as possible. in production sets, the minimum is 12 hours a day, usually for like union sag stuff. So I was running about 14-16 hours a day, also trying to get to class on the days that I wasn't on set, not getting enough sleep, not regulating my diet. So I think that also like really contributed to the flare of my disease.

But yeah, I mean, luckily, around like my sophomore year of college, so I was probably 21-22. If I'm doing the math correctly, I started to just tell people, like when I would get a new job, I would tell my bosses like, Listen, this is the thing that I have every six weeks, I have to go to

treatment. There may be days that I'm not feeling well. And it's it's not because I'm moralized by the industry, or demoralized by the industry. I mean, it's because I'm not feeling well. And I did start to learn that there weren't many people even, like aware of what Crohn's was. So then it became a responsibility of mine to educate others. And as a 21 year old, you know, just trying to get a hold of my health in general, it's hard. So I will say to people, if there's anyone listening, who has some some form of IBD, and is interested in the film industry, it's not impossible. I mean, as long as you're honest with yourself, and the people that you work with, you will find a community of filmmakers or production crew or whatever, who understand the importance of taking care of yourself while also doing your job.

Amber Tresca 8:32

You also had your diagnosis changed during this time. And that's a really big thing. I mean, it's hard enough getting that first diagnosis, although I don't think I'm too far off the mark for a lot of people to say that it can sometimes be a relief, to hear to have a name to it, and then say okay, now here's the treatment, and here's what we're gonna do. Yeah, then to turn it around. And now you've got to wrap your brain around something completely different. Were you even aware about Crohn's disease, you know, and how it's different from ulcerative colitis? or How did this all strike you when it happened?

Derek Mari 9:05

You know, again, I think I'm still learning. I think there's like a misconception that Crohn's is the more severe version of ulcerative colitis. And I think I kind of make that mistake sometimes when talking about my journey, like at first being diagnosed with ulcerative colitis and then being diagnosed with Crohn's. It's not the case at all. But yeah, I mean, when I was re diagnosed with Crohn's, the real battle in the real struggle was that all the medicines that I had tried for ulcerative colitis weren't helping. So I had to do a whole new like trial of different prescriptions and I never tried Humira. But that was talked about a lot as the next step.

And then I mean, I guess we can talk into or get into it further, but um, when I was like, 22, I was so sick that I had such a horrible flare up and I was in the hospital for about a week. And that was the precursor to going on Remicade. So that kind of was like okay, Remicade is my doctor talked about it being like a like emergency drug use because it is intense. You know, it's like a six week infusion for as long as necessary. So I started going on that. And that. Yeah, got everything under control. Luckily,

Amber Tresca 10:26

yeah, it sounds like your disease was severe, though. So it was Yeah. Sounds like it was the right choice that some of the other things probably weren't good or not good into remission for you. So yeah, great to be able to hit it hard in that way. And so that you could move on to do this great work that you're doing. You have a short film that is called crony. Yes. There's so many things in it that speak to the IBD community.

Derek Mari 10:54

Amazing.

Amber Tresca 10:54

I loved it. But how did you get there from doing the other films that you did, many of which, of course, I've also watched and enjoy. much amazing. I've been actually sending them to people. I'm like, you guys, you gotta watch this.

Derek Mari 11:08

That is the best thing. Wow. Thank you.

Amber Tresca 11:10

But yeah, so how did you come around to making this marriage between your health journey and then your career?

Derek Mari 11:19

Yeah, yeah, wasn't my first film, but it was my first film that dealt with Crohn's or any kind of chronic illness scenario, any subject matter about that within the characters. I started writing that film when I was in the hospital. I, it's such a cliché Hollywood story, but I truly was just at my wit's end, and feeling like so alienated from my peers, especially within the film industry. And I was doing a lot of comedy, like improv and sketch at the Upright Citizens Brigade in LA. And through that kind of, kind of found the bravery to like, use personal stories and experiences and implement those into comedic material and kind of finding, like healing through humor, if that makes sense.

And so I'm in the hospital, there's discussions about surgery, there's discussions about prednisone, and which I have done a hundreds of times. And this new mysterious medication, which is an IV, you know, and I was just feeling like, confused, a little scared. And so I started writing about a character, my age with Crohn's. And his journey towards self acceptance, filled with like humor in hearts. And yeah, wrote that script over the following year, and then eventually pulled a scene from the feature length script, and produced it as a short film. It's an eight minute film that we submitted to some festivals. And yeah, the short film uses Crohn's more thematically, because it also comes along with the news of the main characters, parents announcing their divorce.

And that kind of their parallel storylines are that everyone's got their thing that they hide from others that you know, they're invisible struggle that eventually come up and surface and you have to recognize and reckoned with and accept or deal with the consequences. So we use Crohn's more thematically in the short film, but the audience response that we're receiving at film festivals, where people would come up and be like, thank you so much for making like a crummy Tommy joke. It just made me so it was so encouraging. It was so inspiring, and I got to talk to so many people. And then over the past year, we've been on this journey towards producing the feature.

Amber Tresca 13:58

did a lot of people come up to you after seeing your short film and say, I live with Crohn's disease? Or I have a family member or a friend? That happened a lot?

Derek Mari 14:06

Yes, yes. Yes. And it was and to hear them say thank you for talking about it, even though I felt a sense of guilt because the short film is titled crony. And the short film deals more with the divorce of the parents rather than the actual daily struggles of Crohn's disease. But just hearing people say, thank you for talking about Crohn's and like making a joke out of it not you know what I mean? Finding the humor in the struggle is it's empowering to others.

Amber Tresca 14:38

It is in the way your mother in the film deals with it. It's just I think we will all recognize that. So it was really yeah, very funny.

Derek Mari 14:49

Yeah. How often are I I'm in a bad mood and someone goes, Oh, is it your tummy? Are you having a flare? It's like, no...

Amber Tresca 14:58

There's actually a lot in that, because I'm a mother. So, you know, I identify with the parent and but I saw her, you know, her care for you. But also kind of pushing back on that to be like not everything is about my Crohn's disease. Yes, exactly. And also, for instance, you can feel bad. Just it doesn't have anything to do with your IBD. Yeah. When somebody gives you bad news, you can just feel bad.

Derek Mari 15:26

Yeah, exactly, exactly. And this character, especially in the short film is at a place where he would rather treat the disease as its perceived, which is invisible. So he's not ready to talk about it. But fortunately, we are on track to producing the feature, which is where I'm really excited to really authentically represent, like the daily struggles of having a chronic illness, especially one that's invisible.

Amber Tresca 15:55

Yeah, absolutely.

[Music: AIBD Transition]

Amber Tresca

The full length feature film, you have a partner that's helping you to get this film made. And how are you going to go about this, because, as I'm sure you know, depiction of IBD almost never happens in our TV. When it does. A lot of times it's connected to, for instance, stoma, or ileostomy, or colostomy. And it's usually portrayed as really like, a bad thing that doesn't have a life anymore. And we would really love to see that you can still, as many of us know, you can

still have a full and vibrant life living with IBD. So tell me about this about the about the full length feature?

Derek Mari 16:39

Yeah. So about we're recording this in almost March 2021. And in March 2020, right after the world was starting to shut down due to COVID-19. Not to bring that up.

Right, I didn't know if we wanted to pretend just making the podcast doesn't exist. But yeah, that kind of provided the opportunity to start looking at the future film, and putting a focus on the work that would come with trying to see if it was doable. We I partnered with Dan Sema, he is an incredible producer. And he read the script and felt really drawn to it, I won't speak on His behalf. But he does not have any form of IBD. But found catharsis and relatability in the, the search for identity and coming to terms with an aspect of yourself. And those themes are kind of, you know, more universal.

Yeah, we did a budget breakdown in the schedule breakdown. And then we were like, wow, this thing is doable. And we think that there's an audience that would love to see something like this. I mean, myself included. The reason I wrote this was because I wanted to see something like this 10 years ago, when I was just figuring out a diagnosis. So over the past year, Dan, and I have built production assets, such as like, a lookbook, which is like a visual document to show to people to convey our vision. We have the short film, we're attaching talents, we're going to producers and potential investors. And we've gotten to the point where we feel very strongly about the network that we've established and the supporters that we've met with, including Crohn's and colitis organizations and just individuals living with the disease.

And we are getting ready to launch what's called a WeFunder campaign. That's essentially Kickstarter, which is for donations. We funder is for investments. So we are launching our campaign mid March. And that that gives people the opportunity to invest in the film, and then potentially receive a share of the profits once the film makes money after its release.

Amber Tresca 18:59

I want to ask you too about even the name of the film.

Derek Mari 19:02

Yeah,

Amber Tresca 19:02

Even telling people that you have a form of IBD. Like that's something that you have to come around to.

Derek Mari 19:08

Yeah.

Amber Tresca 19:08

It doesn't happen right away. But the name of your film is really taking it to yourself. You're calling yourself a crony. Yeah, you're several years into your disease journey now. But even so, I think that's a really big thing to do. What do you think about that?

Derek Mari 19:27

Yeah, no, I think so too. I think at first, I mean, the film is very, it's semi autobiographical. The character is along the same journey that I am still on, but a little further along, by kind of using crony as a term to describe the feeling of isolation. I'm not like other people. I'm a Crohnie I'm, I feel like an outsider.

Derek Mari 19:54

But then discovering there's a whole community of Cronies and that is such a beautiful thing. That one Once you meet those people and feel like you're part of something bigger, and you're like, Oh, this word that I use self deprecating Lee is actually really empowering. And so that's something that the character discovers. But that's also something that I'm discovering, just by doing this film, like still pursuing it as a feature and continually meeting with people like yourself, who are just part of that community and really awesome, amazing people.

Amber Tresca 20:24

Yes, I always say people with IBD are literally the best people that you are ever going to meet. Because Yeah, I have been through some stuff. Yeah. So. And speaking of going through some stuff,

Derek Mari 20:37

I'm excited. Yeah.

Amber Tresca 20:40

The very act of writing about your diagnosis, your disease, how other people reacted to it, and how you are figuring out your career and just living with it, that is not an easy thing to do. So you said you wrote a lot of it in the hospital? Like, how did that work for you in terms of processing? Did it help you process? Did you learn new things, because I have to tell you, whenever I sit down to write about my own disease journey, like, it takes a while and like, it's sometimes taken me decades to write about things. So I'm always curious to learn from other writers how they deal with the emotions and what their process is.

Derek Mari 21:28

Yeah, that's a really great question. This all started early, like January 2018. So it's been about three years. And the, the script has taken on so many different versions. I think at first, it was simply for myself, it was an exercise in confronting something that I had neglected. And yeah, a form of self acceptance, to implement it into my art, and really just kind of purge those feelings.

Derek Mari 22:01

And I will say that the first draft was an angry draft. I was mad about the disease. And I was mad about how it made me feel in society, and then started sharing it with some friends that I

really trust. And they gave me wonderful notes. And as the script evolved, and became more of a full fleshed three dimensional story, I started submitting it to festivals, and screenwriting competitions, such as like the Sundance lab, which is like a really exciting lab that they do for up and coming filmmakers, and was amazed that it started placing and things and we were getting really positive feedback.

Derek Mari 22:40

Because what felt to me like maybe too niche of a subject matter. It had, like I said earlier, universal implications. Yeah, that's, that's kind of when I was like, oh, maybe this is the thing that other people will want to see. Because up until that point, it was purely for me, which was an exciting discovery.

Amber Tresca 23:02

Yeah, I think that's true. Even like with other disease states, the more people that I meet, who live with rheumatoid arthritis, or you know, another immune mediated condition, we have so much in common. I think we all think that maybe we're in our own disease silo. And we have to do it that way. But there's so much crossover in your short film that you know, the Oh, is that your tummy? Everything. But people that live with other diseases have that same kind of thing that people around them tend to just kind of focus on that thing. And as I said before, like, but we all have a thing. Yes. It's just different for each of us.

Derek Mari 23:38

Exactly. Yeah. Yeah. And again, on this journey towards meeting with people who understand and relate, I've met so many people on the autoimmune chronic illness spectrum. It's not just Crohn's specific or IBD. Specific, really? And yeah, like you said, Everyone understands some facet of this life.

Amber Tresca 24:03

Yeah. The drugs the doctor's appointment. Oh, yeah, sure. Insurance companies like, Oh, yeah.

Derek Mari 24:09

Yeah, yeah.

Amber Tresca 24:11

Let's talk for a minute about how people can find the WeFunder page. Yeah, and also where people can watch the film that you already have out. Plus a lot of other films it was so fun to go there and see all the things that you've done. It was just like a little slick, a little treasure box, so fun. And any social media that you'd like to share?

Derek Mari 24:32

Yeah, first of all, thank you. That's, that's so cool that you checked out our stuff. Yeah, so we just launched our social media for crony. That's where we're posting daily updates and, you know, sharing about our crew our talents, talking about our process to get to where we are today. So you can follow us on Twitter and Instagram at crony movie. One word, we funder

calm. I think if You just search crony on we funder you can find the campaign there, but we'll also be sharing it and posting about it on our social media. And then myself, I'm on Instagram and Twitter at director, Derek.

Amber Tresca 25:14

I will put all of this information in the show notes and on the page on my website about IBD.com. So I just have one more fun question for you. Okay. So many times I ask other people questions, and I really just, I don't even know how I would answer them. What's your favorite film?

Derek Mari 25:31

Oh, my favorite film? Hands down E.T.

Amber Tresca 25:36

No kidding.

Derek Mari 25:38

Yeah, yeah, E.T. And when I talk about this question, people are usually like, is that your current favorite movie? Or is it because you grew up loving it? And I think both. E.T. is such a pure, amazing film. And it definitely was like the first film as a child that I remember watching and being like, oh, somebody made this like, this is art that required work, and thought, and became obsessed with it. And I still love it to this day.

Amber Tresca 26:11

Do you remember how old you were when you saw it?

Derek Mari 26:13

I think and this may age me a little as in like, making me sound like I'm an absolute child. But I think I was five or six when I first watched it.

Amber Tresca 26:27

Yeah. I will just tell you, Derek, that I was in fourth grade when that movie came out.

Derek Mari 26:35

If it means anything, I saw the rerelease in theaters.

Amber Tresca 26:40

Yeah. After you had already seen it at home.

Derek Mari 26:43

Yeah. Yeah. on VHS watching it over and over and over.

Amber Tresca 26:47

Oh, my gosh. That's fantastic, though, being able to see a movie in the theaters after you've only ever seen it on your TV at home. Yeah. Yeah, really wonderful experience.

Derek Mari 26:57

Really exciting, and really just was like the foundation of loving theater and cinema so much.

Amber Tresca 27:04

I love that answer. It was so not what I expected. And I love those answers. The best. Great. Thank you so much for coming on my show. Thank you.

Derek Mari 27:15

Thank you.

Amber Tresca 27:16

Thank you for all the work that you're going to do in the future. I really am very, very impressed with your work.

Derek Mari 27:22

No, that's the best compliment. Thank you so much. I mean, thank you for having me on this and thank you for being so amazing. I mean, we we met just a few weeks ago, but you've already done so much for us and we really truly appreciate you.

Amber Tresca 27:38

Hey super listener! Thanks to Derek Mari for sharing his experiences in living with Crohn's disease and in bringing awareness to the patient journey through his films.

The IBD community is special. Even though we are all over the world, we're still a tight-knit group, and many of us regard one another as family. I think that's never more true than when it comes to supporting one another. That's why I know you'll be excited to view Derek's short film, Crohnie, and his other work at vimeo.com/directorderek. You can also follow him on Twitter and Instagram as @directorderek and the Crohnie movie on Twitter, Facebook, and Instagram as @crohniemovie. That way you can keep up with all that Derek is working on and the status of his full-length feature film.

I will put all of these links in the show notes and on my Episode 91 page on AboutIBD.com.

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

About IBD is a production of Mal and Tal Enterprises.

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

Mix and sound design is by Mac Cooney.

Theme music is from Cooney Studio.

Amber Tresca

There's almost always a bleep in the outtakes.

Derek Mari 29:04

Okay, what kind of bleep are we talking about? Like a little duck quack or are we talking about just traditional sensor?

Amber Tresca 29:15

Hey! You thought the episode was over, but it's not! I want to let you know that the WeFunder campaign for the Crohnie move is open right now! You can head to [WeFunder.com](https://wefunder.com) and search for Crohnie to be a part of it. Go there when this episode really does end and find out how you can help get this movie made. Also, I know you have social media accounts and I know you have friends, so maybe you can share this podcast and about the Crohnie movie on your Instagrams and Tik Toks and Facebooks. Go to [W-E-F-U-N-D-E-R.com](https://wefunder.com) and search for Crohnie, which is C-R-O-H-N-I-E. Thanks a bunch and I look forward to seeing your posts!