

## About IBD Podcast

### Episode 87 - COVID-19 Vaccination With UC Patient Rosanne Mottola

#### Episode Transcript

##### **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 87. My guest is Rosanne Mottola. Rosanne works as a public relations professional at a New York City area hospital and is a vocal IBD activist. She lives with ulcerative colitis, which was only confirmed after years of being misdiagnosed.

Rosanne recently received the first dose of the COVID-19 vaccine. As I discussed on Episode 85 with Dr David Rubin of the University of Chicago, the vaccine is expected to be safe and effective in people with IBD. If you haven't heard that episode or read the transcript available at my web site at [aboutIBD.com](http://aboutIBD.com), I really recommend that you do so. Many of the common questions about the vaccines and vaccination are answered by Dr Rubin. And if you check his Twitter [@IBDMD](https://twitter.com/IBDMD), you'll see that he's received the vaccine himself.

Rosanne is one of the first IBD patients I know to receive the vaccine and I wanted to hear about her experience. She not only was gracious enough to tell me about it but she also gives some great advice on how to advocate for yourself with care providers and friends and family. Once you hear her IBD story, you'll see why she's the best person to give this guidance.

Roseanne, thank you so much for coming on About IBD.

##### **Rosanne Mottola 1:39**

Thank you so much for having me. It's really a pleasure.

##### **Amber Tresca 1:40**

I was trying to remember when we met in person was that 2019 it was day on the hill.

##### **Rosanne Mottola**

I think it was, I believe it was 2019 day on the hill.

##### **Amber Tresca**

I was so pleased to finally meet you and have this connection. And now we can talk a little bit more about your disease journey and what it's been like during the pandemic the past few months and most recently, your vaccination. Absolutely. I wonder if you would first start for me by giving me a little bit about the background of your diagnosis with ulcerative colitis, because during this last Crohn's and colitis Awareness Week, I noticed you did the infographic. And

something that really stood out to me was how long it took you to get diagnosed. So I'd love to know more about that.

**Rosanne Mottola 2:26**

Absolutely. So I was officially diagnosed in May of 2006. And that was in my senior year of college. But I looking back I think that I had symptoms probably from the time I hit puberty around the age of 13 or 14 years old. At the time, I brushed it off as something I ate, you know, or something that I did, or maybe a nervous stomach. But at the time, I definitely think I had IBD symptoms and just didn't know it. It got bad right around the time I was in my senior year of high school. And at that time my parents jumped on it got me to a specialist. I was a little bit anxious about going to a gastroenterologist at the time and sort of insisted on a female gastroenterologist for some reason. And they found someone for me in Manhattan. I live in Staten Island, so it's really not that hard for us to get to Manhattan.

And they did an upper endoscopy, even though I had IBD symptoms of diarrhea and loose stool, and they did an upper GI and they didn't see anything and she quickly diagnosed me with IBS and told me I had anxiety and I needed to relax and calm down. It's a similar story with so many that I've met. And it just went undiagnosed for a while I started college. I was definitely more of a homebody at the time, I didn't go out a lot. I encouraged my friends to hang out at places I felt comfortable.

And looking back at it. I think it was just me, my body telling me that I had this thing going on and I didn't feel comfortable going too far away from my bathroom and my home and it just continued and I managed it somehow until it spiraled pretty much out of control. By the time I was a senior in college. And you know, it wasn't because of unsupportive family or my parents who would have moved heaven and earth to make me feel better.

I just sort of powered through and tried to ignore my symptoms and became comfortable with my routine and ignored it until I couldn't ignore it anymore. So when I was finally, a senior in, in college in my spring semester, right before graduation, I couldn't attend class anymore, I'd gotten so bad. And they took me to a new gastroenterologist, who was only marginally better.

He did a colonoscopy. And I remember being in this, you know, haze of anesthesia coming out of my colonoscopy, there was nobody with me at the time. And he said, Okay, so you have ulcerative colitis, and it's a mild case, and make a follow up with me in a few months.

And I was actually relieved at the time, because I felt like it had a name, what I was going through, it wasn't in my head. I wasn't making up the symptoms. It wasn't my anxiety that I was like, there's medication for ulcerative colitis. So this can be managed, it's okay. And my mom came by and I told her and she immediately started crying. And I felt less comfortable at that point. And it was just a really difficult place to get to. And at the time, I was not getting optimal care, that's for sure.

**Amber Tresca**

Had you heard of ulcerative colitis before he said those words to you when you were in your propofol haze?

**Rosanne Mottola**

Yes. My propofol haze. I did know of ulcerative colitis, just from my own research. It was 2006 I had the internet. And I was doing my own research at the time. And I thought that my journey might lead me to ulcerative colitis, that that my diagnosis might be ulcerative colitis. You know, I think when I, when I was being constantly told I had IBS, one of the things that I was most frustrated with was there's no medication, really to treat it, there's nothing that can help me feel feel better, except for, you know, anxiety, or, you know, managing stress and things like that. But I was actually relieved because I thought that there was a pill that could help me feel better now, and I did not know much about it. And we can probably talk about this a little bit more later in my disease journey.

But I think what made me most nervous right after my diagnosis, and he told me to just follow up in a few months, was that when I started reading online, I was reading really all of these worst case scenarios, I was reading these incredible advocates who had been through such horrible experiences with their IBD. And not everybody gets there. And I think that in the advocacy community, especially the loudest voices are the people that have been through really these worst case scenarios. And so it's really hard for new patients and for parents of new patients and caregivers of newly diagnosed folks to read these stories and just jump to these worst case scenarios. I think, in my opinion.

**Amber Tresca**

I completely agree with you. And being in the j-pouch community. I see that a lot. And I try to remind people that, for instance, I know several people who live with a j-pouch, and they're out living their life, they're not in the j-pouch groups, you know, they don't find the need to be in there. So it's those that are having a problem that are in the groups and so that's why it's so it gets a little skewed so yeah, and especially in 2006, you had you had options. You had treatment options, so that was really good.

When they told you had IBS. Were you going through all of the treatment options, diet. I don't know you know, hypnotherapy anxiety meds, were they doing all of that for you? Did it have any effect at all?

**Rosanne Mottola**

So they did some of it with me. They gave me diet they gave me some medications that were supposed to stop diarrhea as it you know, as I feel it coming on, I would had this one medication that it would put under my tongue and was would dissolve and it was supposed to stop something in a while. It's it's I feel it coming on. None of it worked. Absolutely none of it worked.

And I'm really frustrated by that experience because my disease was progressing. The inflammation was probably getting worse by the minute. And I was following my doctor's orders, but nothing was helping. And I am not. I've gotten better, but I'm not the type of person to stand up and say, I need help. This is not working. You're not helping me. I say, Okay, this

sounds good. I'll try this. And then I never really question. You know, 15 plus years of IBD has helped me be more proactive about my own health. But in the beginning, I, I was this 18 year old kid that wouldn't question the doctor's opinion. And I think it definitely hurt me.

**Amber Tresca 10:51**

What was the turning point? Do you think that you went and got, basically what essentially was a second opinion, like what was the symptoms or the reason why?

**Rosanne Mottola 11:00**

So after being told a few times that I had mild disease, and I needed to learn how to live with it, I, you know, was really struggling at that time. And I graduated college, and I felt like I couldn't hold down a full time job at the time. So I applied for graduate school, because I was determined not to stop my career and to stop, you know, progression in that regard. So I got into my dream school and my dream program at NYU for public relations. And I decided to take on a full time course load, which at the time, seemed more manageable than a full time job, but obviously, was very naive of me. So I started taking full time classes at night, in Manhattan with an hour and a half commute each way, at least, where I would not eat my entire day. So I could make my commute in.

And for those outside of New York City, this might not make much sense. But I live in Staten Island. So I was taking the Staten Island Ferry to Manhattan, which was a 30 minute ride. I opted for this ride, because there was a bathroom on the board versus getting on an express bus where I could be stuck in traffic. So I would take the ferry to Manhattan, and then take a subway from the ferry to Midtown Manhattan where my classes were. So all in all, it would take about an hour and a half. And I knew every bathroom on their route like the back of my hand. So I would go and have class and I would do the journey back home, which often took longer, because it was off hours at the time and things didn't run as frequently as it was at six o'clock. And I'd eat at 11 o'clock, and I'd go to bed. And then I do it all over the next day. So that lasted about four weeks before my body completely broke down. I needed to withdraw from class from really bad symptoms. And I knew that it gotten bad when I was on the subway platform one night and I couldn't turn my neck looking for the subway to come and I couldn't turn my neck. And that night, I couldn't breathe. The end of this all was that I ended up getting pneumonia, which turned into a staph infection which turned into double pneumonia. And I was hospitalized for pretty much the whole fall of 2006. And while I was in the hospital, I got c diff.

It was right after I was discharged from the hospital. And I was having all the symptoms of C diff and I had called my gastroenterologist on a holiday weekend in pure agony. And I thought it was my IBD but it was c diff. And you wouldn't take my call because it was a holiday weekend. So that's when I decided to get another opinion a third opinion here. And actually the head of the NYU program who was wonderful about helping me through this said I have this great doctor out of New Jersey, my daughter has Crohn's disease, you should go see him and New Jersey seems so far away. It seems far away at a time where I couldn't spend 15 minutes outside of the bathroom. I got on the phone with this doctor and he spoke to me over the phone

At the time, there was really no tele visits like this. He wrote a order for lab work for me to confirm the C. diff, because he was pretty sure that's what it was. He pretty much saved my life. He's still my gastroenterologist to this day. He answers my phone calls when I need him to he, he's on top of all of the latest medications and treatments and research. And he To this day, I credit him for really saving my life. I went back in the hospital with C. diff, at his hospital in New Jersey. And he nursed me back to health. And is my partner really in this journey to this day? Are you still considered to have mild disease? Or was that ever changed? So right after all this, I would say my most tumultuous years with my IBD journey was probably the first four or five years, it was definitely bordering on moderate to severe for a while until they found the right mix of medications for me, in 2010, which was four years after my diagnosis, I was just engaged and planning a wedding. And it was probably one of the worst disease states that I was in for my diagnosis until the present time.

And at the time, my my gastroenterologist who I credit saving my life said, I think you need to see somebody else just for a second opinion, I want you to confirm what I'm thinking. And that is that you might need surgery, and you might need to have your colon removed. It was a very emotional time of my life to be planning a wedding and trying to come to terms with with this. And he referred me to someone at Mount Sinai in Manhattan, who he knew and who was a fantastic doctor. And I've actually reconnected with him and IBD down the hill and some other locations. And he said, I think it's a little premature to talk about surgery. Let's try this one mix of infusion meds, and other immune suppressants and other medications. And once I got on that mix, it just clicked and I started feeling better. And I got through my wedding and when my disease really calmed down was Believe it or not when I had my children?

**Amber Tresca 17:46**

Yeah, a lot of people say that actually, as you well know. It can get worse, it can get better, it can stay the same.

**Rosanne Mottola 17:51**

Yes, I was lucky.

[Music: About IBD Transition]

**Amber Tresca 18:00**

Advocacy and activism are obviously very important to you even though your diseases, your disease was considered mild. You went through really horrible complications and were hospitalized for a long time. Was that what spurred you to do something like a day on the hill and to get involved with the foundation and the way that you have?

**Rosanne Mottola 18:20**

Yes. So one of my first Crohn's and Colitis Foundation events was in Manhattan, and it was about managing work and insurance with IBD. And just to date myself, this was 2006 or 2007. And it was before the Affordable Care Act, the woman in front of me stood up and said that her

five year old was just diagnosed with Crohn's disease. And her family of five was just dropped from their insurance because of his diagnosis. I just cried my eyes out for this one. And that's sort of how I got interested into in advocacy.

And then I got involved in the beginning it was even hard for me to tell people my diagnosis. But as the years went on, and I became more comfortable with my diagnosis and telling my story, the more I felt an obligation to tell my story. When the Affordable Care Act's was being debated and patient protections were being debated. I realized I'm I'm only in my early 20s. I have my whole life to live with this disease. And nobody should be dropped from their insurance because of a disease that nobody caused. This was just something that happened to me. And, you know, whole families shouldn't be dropping from their insurance because one child has a chronic disease that they're going to have to live with their whole life. So that's sort of how I got involved in advocacy. I went on a few congressional visits in districts with the foundation during the Affordable Care Act talks. And from there, I went to my first day on the hill and got completely hooked in advocacy work.

And, you know, my continuing interest in politics has helped this as well. And I've gotten into healthcare advocacy and other social justice issues. And it really means a lot to me.

**Amber Tresca 20:47**

Yeah, and most recently, you've been involved in advocacy, also, in regards to the pandemic, through your work. So I want to hear a little bit about your work, because it was through your job that you actually received the first dose of the vaccine. And I guess I don't know which one you receive. So you can tell me about that, too. So why is it Roseanne that you have gotten the vaccine already?

**Rosanne Mottola 21:11**

So as I mentioned, I went to school for public relations and corporate communications and ended up somehow in the healthcare communications fields, somehow, but actually, it was, it was really by chance. At first, when I graduated grad school, it was 2009. And it was right at the beginning of the recession, the whole financial system had collapsed at the time. And here I was looking for my first full time job, one of my professors had recommended me for an open position, and they were few and far between at the time. And it ended up being in pharmaceutical Public Relations at an agency.

And that's sort of how I got pushed in. I wasn't necessarily interested in it at the time. But I've sort of stayed in that sphere of health care communication since then, about three years ago, I got a job at a hospital, one of New York City's 11, acute care public hospitals, doing public relations and Public Affairs.

So at the hospital, I do employee communications, external communications, and I do some also advocacy and, and elected official outreach. And in this role, I am all over the hospital, I'm taking photos, I'm escorting media around, holding Town Hall sessions for staff members, and so on. And because of that, I'm exposed, you know, to everything. And since March, this has been the COVID 19 pandemic all day long.

So with that, when the vaccine was first available for healthcare workers, they did a very slow and gradual rollout. They started with the most exposed departments, the ICU and the emergency departments. And, and slowly, they rolled it out to each department across the hospital. And finally, on New Year's Eve, I got word that all administrative staff were now able to be vaccinated. And I immediately made my appointment for the following Monday and received the Pfizer BioNTech vaccination last Monday, which was January the fourth.

**Amber Tresca**

How did that feel? emotionally? And then how did that feel? Physically, I think I feel like physically is the lesser of the two but you can tell me whether I'm right or wrong on that.

**Rosanne Mottola**

Sure. Um, it was definitely an emotional experience. It I described it to a friend recently, as you know, when the needle went in my arm, it was similar to the moment I gave birth. I said, you know, when you give birth, there's this moment where your body is relieved, as well as your emotions sort of take over you feel this extraordinary amounts of happiness. And that was what the getting the vaccination felt like after 10 excruciating months of going through this. You know, getting that shot felt relief and extraordinary hope and and joy for what was to come. Physically, I barely felt the needle going in. If that's a concern for you, I didn't feel anything, and I felt fine afterwards. The following day. I got a little flushed at one point, I had never had fever. But it was very minor compared to the stories I've been reading of people that have contracted COVID-19.

**Amber Tresca 25:11**

Right? And did you check with anyone from your healthcare team before you received the vaccine?

**Rosanne Mottola 25:18**

So when the vaccine was first available to health care workers, they told us that they anticipated that within three weeks, all staff in the hospital were going to be offered the vaccine. So I had a telehealth visit with my gastroenterologist. And we chatted a little bit about the vaccine, which he immediately said if it's offered to you take it right away. And that was what I was hoping he was going to say. Basically, he also mentioned that there might be some efficacy concerns in terms of how, how much protection IBD patients or those who are immunocompromised might receive and that will keep an eye on it, but that I absolutely should get the vaccine, if it's available to me. I also started watching Crohn's and Colitis Foundation had some amazing roundtables on on Facebook, and also following some other epidemiologists and other IBD doctors who were really following the science on a daily basis. And from what everything I read, there was really not a concern for me to get the vaccine, and I jumped on it.

**Amber Tresca**

Right. And it's my understanding, and it has been and from talking with Dr. Rubin a couple

episodes ago specifically about the vaccine. And then also I'm sure that we follow a lot of the same yes positions and what they're saying that yes, it's there's not a concern that there would be some adverse event that would happen, the concern is, is that we might not mount the same robust immune response. But I think as time is going on here, there that is becoming less and less of a concern. And what was said to me was, at least having some immune responses better than none, and possibly getting COVID-19. So was that was that kind of what your doctor said, as well?

**Rosanne Mottola**

Absolutely. That was exactly what he he told me. And, you know, as more of us with IBD, get the vaccine. And with time, we'll see how our responses are and how we keep our immunity up. And if there needs to be a booster there needs to be a booster in my opinion. I'm okay with it. I get a needle in my arm every few weeks for infusion treatments anyway, one more needle, what is it? If it protects my family? If it protects my loved ones? If it protects my grandmother who I see on a regular basis? Then then so be it. I'm all for the greater good here.

**Amber Tresca 28:12**

Yeah, totally agree. I said, If I had to get it in my eyeball, you know, blow dart from across the room, whatever it is, just give it to me.

**Rosanne Mottola 28:21**

Exactly. And I actually felt kind of bad. Not that I felt bad about getting the vaccine so soon, but I I feel privileged. And I feel upset that not everybody else is having this opportunity that I got, I think of I have 290 something year old grandmothers who still haven't been able to get their vaccine in New York. And I just, I wish I could have put them ahead of me in line in some way. And I feel like all of my fellow IBD friends, I wish that we could all already have our vaccines and already start building immunity so that we can relax a little bit and stop having to panic all day long about this pandemic and what it would do to us as immune compromised people.

**Amber Tresca 29:22**

Absolutely. And as we all know, the high stress levels are not our friends.

**Rosanne Mottola 29:30**

No.

**Amber Tresca 29:31**

So in that regard, you're now a very experienced patient in so many ways, having been first diagnosed with what they called IBS and then a trial by fire to what was then diagnosed as mild disease, but maybe sounds like maybe that really wasn't the case. And then some complications including pneumonia, and C diff. Do you have any advice for a newly diagnosed patient?

**Rosanne Mottola 30:00**

Yes. So I often tell IBD patients, you know, it gets better. And that doesn't mean that your disease is immediately going to get better as time goes on. But the level of acceptance gets



better, and your comfort level gets better. And you will feel better about your diagnosis as time goes on. And at first I was my immediate friends knew about my condition, but I was silent to everyone else. And as time went on, just being able to talk to my employers, talk to my professors, talk to anybody in the world about what I needed as someone with IBD. And feel more comfortable about saying, hey, I need to use your restroom right now. And, hey, I don't think I can go to this social function tonight, or just feeling okay with, with not being that stereotypical kid or teenager or worker, even even, you know, a full time employee have somewhere, to just be able to stand up for myself and speak out. I would tell people not to take to heart everything that you see online.

Well, advocates are wonderful resources, and are so willing to help, it doesn't mean that you're going to go down the same path that they are. And that was something that I had a really hard time with. I consider IBD to have profoundly changed my life. But with that being said, I never had surgery. And that is not what you would see if you went down the IBD journey on Google, you would see a much different progression. So just because it happens to someone else, these are very individualized diseases, that doesn't mean that that's going to be what happens to you, and to speak up for yourself with your medical professionals.

If something does not seem right. Don't wait for years, like I did. Speak up for yourself demand better if you're still not feeling well. And someone's telling you that that's the best it could be.

Find somebody who you can work alongside with as your medical professional in this journey, and it will get better.

**Amber Tresca 32:40**

Roseanne, thank you so much for sharing your journey for sharing your experience in receiving the vaccine. And for being such an amazing IBD activist. I really appreciate all you do. Thank you so much.

**Rosanne Mottola 32:55**

I've been a longtime listener. So it's exciting for me to be on and talking to you. And I hope people find some kind of comfort in what I have to say and please go get vaccinated.

**Amber Tresca 33:15**

Hey super listener! Thanks this week to Rosanne Mottola for sharing her IBD journey and her experiences in receiving the COVID-19 vaccine. I will put links to more information in the show notes and on my Episode 87 page on AboutIBD.com.

As I was editing this episode, what became obvious to me is how Rosanne's story held both the worst and the best examples of IBD care. In the beginning she was misdiagnosed and her symptoms were minimized. That continued even after her diagnosis of ulcerative colitis. Symptoms and evidence of disease don't always match up. With IBD, you can have symptoms and no visible disease. On the flip side, you can also feel well and have your tests come back saying that your disease is active. In Rosanne's case, her symptoms were impacting her quality

of life significantly and her disease being undertreated resulted in her experiencing complications.

She got on the right track when her doctor saw that they needed an opinion from someone that was more experienced in treating IBD. They asked for some help, received it, and Rosanne got the right treatment for her. This is how all of our disease journeys should be managed but of course, that's not always the case.

Until we all receive the individualized treatment we deserve, you'll find me on all social media as @aboutIBD, working to educate patients, care providers, legislators, industry, and the public about IBD.

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.

[Bleep]

**Rosanne Mottola 35:10**

And I swore. Which I told you I wouldn't do.

**Amber Tresca 35:14**

And now I have that recorded forever. [laughter]

**Rosanne Mottola 35:19**

I have some Staten Island in me. Believe it or not.