About IBD Podcast Episode 109

Colitis Conversations: Treating to Target

Setting goals is an important part of managing IBD. But after controlling symptoms: what other goals do patients have? They can be anything from being able to go up and down the stairs, to cooking a meal, to going back to an exercise program.

Treating to target is a concept that helps in goal-setting. But patients might not be using this method with their clinicians. Dr Neilanjan Nandi, Associate Professor of Clinical Medicine and IBD specialist at the University of Pennsylvania, Perelman School of Medicine and Jacklyn Green, ulcerative colitis patient, writer, and IBDMom, dig deeper into the idea of treat to target from both sides of the equation.

Concepts discussed on this episode include:

- How the Fecal Calprotectin Test Is Used in IBD
- What Is a C-Reactive Protein (CRP) Test?
- Erythrocyte Sedimentation Rate (Sed Rate) Overview
- The Effect of Nicotine on IBD
- A Gutsy Feeling

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Episode transcript and more information at https://bit.ly/AIBD109

[MUSIC: IBD Dance Party]

Amber Tresca (00:05):

I'm Amber Tresca and this is About IBD. It's my mission to educate people living with Crohn's disease or ulcerative colitis about their disease and to bring awareness to the patient journey.

Welcome to Episode 109!

This podcast is part of the American Gastroenterological Association Colitis Conversations program.

For an unpredictable condition like IBD, setting goals is an important part of managing the disease. Getting symptoms under control is significant because it allows people to get back to their lives.

But after the crisis of a flare-up is over, it's time to look at other goals, which could be anything from being able to go up and down the stairs, to cooking a meal, to going back to an exercise program.

Treating to target is a concept that helps in setting these goals. However, it might not be something that is familiar to some patients.

Amber Tresca (00:48):

That's why I asked Dr Neilanjan Nandi, Associate Professor of Clinical Medicine and IBD specialist at the University of Pennsylvania, Perelman School of Medicine and Jacklyn Green, ulcerative colitis patient, writer, and IBDMom, to dig deeper into this idea with me.

Dr Nandi defines treat to target for us and Jacklyn talks about how she and her doctors have been using this concept to help her achieve her goals. You'll want to stay for the end when Jacklyn tells us what happened the first time she brought a stool sample to the lab and Dr Nandi gives us an IBD research history lesson on the unfortunate mice who received tobacco smoke enemas.

Amber Tresca (01:25):

Our topic today on this Colitis Conversation is treating to target, something that probably a lot of people have not heard of. And so we want to dig into this deeper and explain what it is. And I have two guests with me. First of all, I have Jacklyn Green. Such a pleasure to have you finally on the line, Jacklyn, since we've been corresponding and talking via social media for a long time, actually.

Jacklyn Green (01:50):

Yeah. It's been years. Thank you for having me, Amber.

Amber Tresca (01:53):

And then we have an About IBD favorite. Dr. Neil Nandi is with us again today. Thanks so much, Dr. Nandi, for coming back on About IBD.

Dr Neil Nandi (02:01):

Absolutely, Amber. Thanks for asking me to come on. I'm excited.

Amber Tresca (02:04):

Me too. So, treat to target. This is something that people with IBD and their IBD teams need to think about in terms of treatment. But first of all, I want to understand what that means. So I wonder, Dr. Nandi, if you could tell us what is treat to target in terms of IBD?

Dr Neil Nandi (02:25):

Sure. So treat to target means that doctors have certain goals of care when it comes to helping a patient with inflammatory bowel disease, feel better and get better. And it's important that patients know what those goals are. So doctors say, treat to target, because they're checking certain markers of healing, different markers, and then they adjust the treatment to get to those targets.

Amber Tresca (02:51):

That's a really concise explanation. I love it. And how do you work with your patients on a treat to target goal?

Dr Neil Nandi (02:58):

So, I begin by explaining, what's the point of treatment, right? We have short term goals and we've got long-term goals and, Jacklyn, no doubt I'm sure you can relate to this too. As a patient, we don't want symptoms to hold us back from life, so we don't want flares.

Jacklyn Green (03:14):

Absolutely.

Dr Neil Nandi (03:15):

And so it's the short-term goals of making sure we're in clinical remission, but then there's some long term goals that are really important. And that is that we have gut healing, that the lining of our intestine is totally healed, the lining of our intestines called mucosa, so we call it mucosal healing. And how might I know that the inside lining of your colon is healed? I have to look with a colonoscope. Jacklyn, do you like colonoscopes?

Jacklyn Green (03:42):

Oh, I do. I enjoy them. Sure. Who doesn't?

Dr Neil Nandi (03:48):

Yeah. Yeah. The sarcasm is just dripping. Yes. And nobody, nobody loves colonoscopes. Nobody loves the prep and all. So we have to look at other ways to evaluate healing, other than just mucosal healing, which is currently, in 2022, the gold standard. And that's looking at laboratory markers, making sure that anemia has resolved, inflammatory markers like ESR sedimentation rate, or CRP, C-reactive protein, have become normalized. We also look at stool markers of inflammation, and this is fun. This is good for all our patients to know if you don't, which is that

there's a stool test that looks for inflammation in the colon. It's more sensitive for colon than the small intestine, and that's called stool calprotectin.

Dr Neil Nandi (04:37):

And if the number elevated, it suggests active disease. And if you check one before a colonoscopy where there's disease, you can correlate the two. And instead of scoping people too frequently, you can check this every three to four months, as you adjust treatment, while you treat to target, you treat to heal. You want the Calprotectin normalized, the ESR, CRP to normalize, the anemia to get better. And then six to nine months after starting a definitive treatment and optimizing it, you check a colonoscopy to look for mucosal healing. And that in a nutshell is what we refer to as, treat to target.

Amber Tresca (05:12):

Perfect. Thank you so much for that explanation. I think sometimes a treat to target approach also means that patients need to be empowered and need to advocate for themselves. Jacklyn, have you ever done this treating to target and have you had to advocate for yourself to make sure that your treatment is getting you to either your treatment goals, as far as healing and symptoms are concerned, or even your life goals? How have you done that with your team?

Jacklyn Green (05:41):

I have. We didn't call it treat to target. I didn't know that, that was a thing until you asked me to come on the podcast. So I was actually getting into the research and I love that explanation, Dr. Nandi-

Amber Tresca (05:51):

Awesome.

Jacklyn Green (05:52):

... that was great. So not specifically by name, but I am currently in remission and my doctors, both... I have a primary care doctor and a GI right now, and they both monitor everything that you just went over and I have a colonoscopy this year. So I get to go through the joy of all of that monitoring, mucosal healing, and making sure that everything is still on target. I've been in remission since I was pregnant with my daughter. So basically it's been monitoring for the last three years. So my treatment goals have definitely changed over time as my life has evolved. When I was diagnosed with ulcerative colitis, I was 24 and I had just started my first big girl job.

Jacklyn Green (06:39):

And I was moving in with my boyfriend, and living the 24-year old life, going canoeing and kayaking, and doing yoga, and I could go to the beach whenever I wanted. I was enjoying everything. My goals at that time, when I was starting to have symptoms, were to stop having these symptoms. I wanted to stop running to the bathroom. I wanted to stop bleeding. I wanted it all to stop, so I could just go back to being 24 and having fun. And now I'm a wife and

stay-at-home mom. And that last role is the most important thing in the world to me. So right now my treatment goals are around having the energy, and the presence to care for my daughter and to monitor any symptoms that might come up and get them before they get worse and stay in remission.

Dr Neil Nandi (07:38):

Jacklyn, I got to interject. I love how you talked about all the things that you did at 24, what you're doing now as a mom. And as we go through life, our priorities change, what gives us self-fulfillment and enjoyment out of life changes. But it's that, that's extremely important. So like in clinic, when we do clinical trials and we're examining patients, or we're just doing a regular history with the patient, we ask the same boring questions. And to our listeners, how many times does your doctor ask you annoying questions about your bowel movements, abdominal pain, how many times do you go? How much blood? Do you go at night, et cetera, et cetera.

Dr Neil Nandi (08:15):

But there's so much more that's missed in these clinical trials scenarios or question questionnaires or the basic H and P of a patient in the visit. And so I think it's really important that docs or patients relate to their doctors. That, doc, my disease is preventing me from going canoeing or taking care of my baby or whatever it is. And I think that's a really easy way to help people gauge whether they're excelling, and that, that their disease is working. And I say this because I think if there's clinicians listening to this, it's a really easy question to ask.

Dr Neil Nandi (08:49):

And I also have found some of my patients sadly have gotten used to their symptoms, and so maybe have made compromises. And so they may not know it. It's just taken its toll over time. They're like, well, I used to do that, but I don't do that anymore. And you ask a little bit more, like, oh, well that's not like a great hobby. Why don't you collect stamps anymore? Just kidding, that's not a great hobby, but I don't think... But there's so much more cool stuff to do, but... My dad was a stamp collector. I never got into it, but...

Amber Tresca (09:17):

Oh, okay. I was going to say, I have a little friend who's a stamp collector. So...

Dr Neil Nandi (09:20):

I'm just joking. It's just for laughs, people. Don't send hate mail, but, no, you may lose touch with that. And so sometimes, that's something that we need to tell our docs, and doctors or clinicians need to ask their patients, what is this disease preventing you from doing? And maybe that's our goal. When you tell me you walk back in the door and you sold a stamp for $500, we high five.

Jacklyn Green (09:48):

Absolutely. It's about being honest at first with yourself and figuring out what a good day looks for you. What makes you feel alive and human, and then talk about that with your doctor. Before you go to the appointment, think of what those things are. And if you want to get back to that, those are your goals. You have to take an active role in knowing yourself in order to take an active role in your care.

Amber Tresca (10:11):

Jacquelyn, did you ever have one of those light bulb moments, when you realized that you needed to take control of your treatment goals and advocate for yourself in a stronger way than you had been doing?

Jacklyn Green (10:21):

Yes, absolutely. So, the big light bulb moment for me was when I had to search for a new primary care doctor. My primary care doctor left the practice, and I was going to the next one that was at the practice, a newer person. It was someone who'd actually been there for a long time. So I got switched. I went in for a physical. I had just been diagnosed with UC about two months ago. So I knew that I needed to build my team. I knew I needed support. I had no idea what I was dealing with. And they had me get in a gown. She brought in the medical student, which normally I'm totally okay with, but this time I wasn't asked. I don't know if at this office it's just standard that they just...

Jacklyn Green (11:07):

I hadn't been in a while. Like I said, I wasn't really a patient of any sort before I got diagnosed. So I'm not sure about that. But the medical student stood in the doorway and the doctor came in, she introduced herself and immediately opened my gown. I sat on the table and my gown was open, and she immediately was barking out statistics to the medical student, whatever my heart was, my lungs, et cetera, as she's feeling things and going through. And I felt like a timestamp. I did not feel like a human. I was sitting there and I'm like, I'm Tuesday at two o'clock. She's marking the boxes, and I'm Tuesday at two o'clock. I'm not Jacklyn who just got her first pay girl job. I'm not Jacklyn.

Jacklyn Green (12:04):

Finally she finished doing what she was doing and I'm pretty sure I was just in shock that it was actually happening. But as she's washing her hand, she looked over her shoulder and she said, so what are you doing here? And I remember shaking my head like I was dreaming. And then being like, I was recently diagnosed with ulcerative colitis and my doctor left the practice. So I'm looking for a new primary care doctor to join, to build my team. So I have the support that I need. And I will never forget her. When she looked over her shoulder at me, she said, "Well, that's stressful." And that was the end. She asked me if I had any questions, and I just looked at her blankly. I know there were a million things I could have said, but I said nothing, because I was just so shocked.

Jacklyn Green (12:52):

And I left, got in my car and I was like, can I switch doctors? Do I have the ability to choose my own doctor? How do I even start doing that? And this is 2013. You couldn't quickly Google anything from your phone. Maybe if you had the internet on your phone back then, but I didn't, back then. I was like, well, I'll call my insurance company. Maybe they can tell me. And that was my first step into advocating for myself. I called my insurance company. I found out that yes, I do have the ability to choose a different doctor. And they sent me a website that I could choose one from.

Jacklyn Green (13:37):

And that was where I took the next step. And I found the absolute best primary care doctor. She could be listening to this. I know she does. If you do, thank you. You're the best. I was going through my history and I was like, I need to send her flowers. She has done so much for me. But if I hadn't taken that step, I would still be Tuesday at two o'clock. I wouldn't be Jacklyn.

Dr Neil Nandi (14:03):

You are so much more than Tuesday at two o'clock and, Jacklyn, I just want to apologize to you on behalf of all medical education professionals, because one of the first etiquettes of teaching medical students, residents, fellows, house staff, is introducing anybody new, anybody who's really external to the patient clinician relationship, to the patient, and asking for their permission, explaining why they're there. And of course above all else, talking to you, not as Tuesday at two o'clock, but as Jacklyn, and I'm so sorry that happened to you. You should never have to tolerate that, and I know you never will. And I'm glad that's probably the biggest thing of all this entire talk is what you advocate for yourself. You're your biggest advocate.

Jacklyn Green (14:48):

Yeah. And thank you for saying that. You didn't need to do that, and I know majority of doctors are not that way. It was my awakening moment and I will never forget it. That's for sure.

[MUSIC: About IBD Serene]

Amber Tresca (15:23):

But what about setting expectations? Do we just say the sky's the limit and let's just go for it?

Dr Neil Nandi (15:29):

I think first off in terms of setting expectations, it's really important for me as a doc to tell my patients not to compare themselves to someone else, because I think that it's really easy when we're given this label, this diagnosis, that we compare our story to another person or our response to a drug or a food or a supplement, to another person. And that's normal. That's natural, it's human nature. But I know that every single one of my patients is different, uniquely different. And so we can't expect that everyone's going to behave the same or react the same, or improve the same. That said, when you talk about you said about goals, I try to be practical. It depends on where we are in the disease state. What point do you come?

Dr Neil Nandi (16:12):

If you're very, very, very malnourished and having got the right treatment, we have smaller baby step goals. We still have positive goals going forth to succeed, but they may not be running a marathon yet. It might just be, let's introduce nutrition, let's gain weight, let's get physical therapy going, let's get you back to less times in the bathroom. Just small goals, but making progress. And then once we've rebuilt you and you have done all the work that it takes to get there, which a lot of the credit goes to our patients for taking the meds, and going to the visits, and getting the labs and stool studies done, once they've done that and they've gotten better, then we can start thinking about even bigger goals if it comes down to physical endurance.

Dr Neil Nandi (16:51):

But I think not comparing one patient to another, having themselves compare themselves to one another and then, probably baby steps long term, and then recognizing from the outset, what the limitations might be, based on side effects or surgery or whatnot. But I will tell you, and then I'll shut up, but most of my patients are stronger than I probably ever will be, and have accomplished more things physically, despite having some of these physical distractions of side effects or surgery, than people who are blessed with good health, and didn't need to see a doctor. And that always amazes me. And so there's a limit to the physical ability. There's also almost endless capacity of what the mind and will can do.

Amber Tresca (17:45):

That's why IBD people are the best people. I'm just kidding, but...

Jacklyn Green (17:50):

Absolutely.

Amber Tresca (17:50):

No-

Dr Neil Nandi (17:50):

True. That's true.

Amber Tresca (17:52):

I do believe that, that's true because once you have seen... Jacklyn, you are talking about how you were 24, and you just wanted to live your life. But that made you see how your life was being impacted by your IBD and you probably made decisions about what you wanted to do in the future, because you didn't realize how sick you could get.

Jacklyn Green (18:15):

Yeah, absolutely, a hundred percent. And even just the adjustment of realizing that I wasn't probably going to be able to do some things, or at least not on the agenda that I had originally

planned, I had to go through that. It is a tough process, but you grieve it and you get through it, and you keep going. Like you said, Neil, that you take one small step at a time. It's so uncomfortable not to call you Dr. Nandi, but I will call you-

Dr Neil Nandi (18:51):

Call me Neil, Hey you. I've responded to words, don't worry. Neil's good.

Jacklyn Green (18:58):

But it is exactly like you said, it's one small step. I remember for me, when I lost a ton of weight and a ton of strength, and I was anemic and this big, and I had a corgi and it was nothing to pick him up and carry him upstairs. He is a corgi, he couldn't go up the stairs. So when I got home from my stint in the hospital, I couldn't pick him up. And so my goal became getting strong enough to pick my dog up again. And then from there, it was, can I do a plank? Can I get back to yoga? Can I make it this far without running to the bathroom? Can I... et cetera. It goes on from there for individualistic. But it's like you said, the disease is different for each person, and you have to look at each person in those small steps.

Dr Neil Nandi (19:51):

But look, you illustrated beautifully, you said you came home from the hospital and you made small incremental goals that you accomplished. And now you're back to being strong, holding a baby, far more heavy than a corgi. But, yeah, I think that's important and I'm glad you asked the original question because I think sometimes, from what my patients have told me that, if they're not well, and they're flaring, they look at how they are now in that moment, and they're comparing their old self when they were healthy.

Dr Neil Nandi (20:28):

And they're like, how do I get... They're impatient, understandably, and they've a right to, impatient to get there, and when they realize that, oh, I'm too weak to get to that point, it feels so depressing.

Jacklyn Green (20:37):

Absolutely.

Dr Neil Nandi (20:40):

It's a heavy weight, it's frustrating. But I think redirecting and saying, no, I will get there. It's just going to take steps to get back up there, incremental steps, just like you did Jacklyn, and you will.

Jacklyn Green (20:51):

Right. And some days it's just getting out of bed, that's one step and it doesn't have to be every day you're getting stronger. Some days you got to wait and then you'll get stronger again.

Amber Tresca (21:05):

So, Jacklyn, was there a time when you had a goal that was just a little bit out of your reach and what did you do to get around that and get back on track mentally and physically?

Jacklyn Green (21:17):

Yeah. I mean, oh, yeah. Okay. Let me start with when I was initially flaring, when I first was diagnosed, I continued to fail at every treatment. I wasn't getting any treatment goals accomplished. I wasn't getting anywhere. I was going backwards. And eventually I was able to get there and get stronger again. It was just about finding the right care team and the right treatment and the right approach. And then again, more recently, treatment goals changed, and when we decided to discontinue the use of my biologic, at the time, I had been in deep remission for a long time. It had been, I want to say, like four years at that point, maybe three years.

Jacklyn Green (22:12):

And I was having a hard time with the travel to my infusion center. It's about an hour and a half away, taking the time off work, and recovering. The side effects were getting worse. So, I was having a hard time with it, and my mental health wasn't so great. We had also gone through a miscarriage and I was just tired of everything and I wanted a break. And my doctors knew everything. And we all knew that there were cases of people coming off of their biologics in deep remission and staying there. And the goal was that I would be one of them. And so we all got on the same page. We all talked, and we were monitoring, and I continued to do the blood work and the stool samples and everything needed.

Jacklyn Green (22:57):

And it was great for about six months. And then some symptoms started showing up, and the plan was that I would immediately contact my doctor, which I did. So immediately I contacted my GI and we started the testing, I think I had been scheduled two months out at that point for lab. So they just pushed it right away. And then I got it in, and there was just a little bit sign of slight inflammation in my blood. So then we decided to schedule a sigmoidoscopy, and we scheduled that. And then I found out I was pregnant a few days before the sigmoidoscopy and my symptoms stopped. I know, this is not common, listeners, not a common thing for pregnancy. Please don't use this as an example. This is just goals changing.

Amber Tresca (23:48):

We should all just get pregnant. That's what we should do. You're not feeling…

Jacklyn Green (23:51):

That's right, it’s a miracle. Not common. But I did go... Here's one that maybe you won't want to go through this. We ended up doing the procedure awake, no medication, nothing. So if anybody wants to talk about that…

Amber Tresca (24:08):

I've had a few of those. Yeah.

Jacklyn Green (24:09):

It's not so bad.

Amber Tresca (24:10):

It's not that bad.

Jacklyn Green (24:10):

And I was in great care. They were amazing. But the nurse before they took me back, she's like, what? You're not getting put under? I'm like, no. So-

Dr Neil Nandi (24:20):

That used to be the standard way, no sedation, and a flexor can be done gently, nicely, within reason.

Amber Tresca (24:29):

It can?

Dr Neil Nandi (24:30):

Yeah.

Jacklyn Green (24:31):

Yeah. Yeah.

Dr Neil Nandi (24:31):

But not something we love. Everyone does love the groovy drugs, and when we can give that, we try to be humane. I think that's appropriate too.

Jacklyn Green (24:40):

I guess more mental than anything else.

Dr Neil Nandi (24:42):

Yeah, yeah.

Jacklyn Green (24:43):

Yeah. Yeah. They were very soothing and somebody actually came in because they thought I was asleep. Somebody actually came in the room to talk to the doctor, and the doctor was like, you got to go, she's awake. And they were like, oh. So funny things happen. But anyway, after

the procedure, there was no signs of inflammation, so whatever happened, my body is cooperating still.

Dr Neil Nandi (25:11):

Good for you. Good for you.

Jacklyn Green (25:12):

Yeah. It's been great. And we continue to monitor. So the treatment goals still are monitoring, and, like I said, I have a colonoscopy again this year, will make sure that everything is still healing and good to go. That is my treatment goals. We achieved them, we didn't, we achieved them, we didn't, we adjust and make changes as needed.

[MUSIC: About IBD Piano]

Amber Tresca (25:46):

Dr. Nandi, I think it might be fair to say that not every patient and their team is working from this model of treat to target. Do you have any advice or thoughts for patients or for providers on how to begin this discussion and then how to begin to think of treatment in terms of goals?

Dr Neil Nandi (26:11):

Yeah. That's a big question, but I'll try to answer it. I think for patients, something to do is listen to this podcast and share it with your community of IBD friends and family, because, even though treat to target is a concept that's been around for a long time, it's not always evenly practiced or consistently practiced. And I think it's extremely important that patients know as much as the doctors do. I'm going to give a shameless plug for two websites that give teach on this. One is my own fitwitmd.com.

Dr Neil Nandi (26:52):

And the second, it's a link from that site is agutsyfeeling.org. It's an educational grant-funded project that talks about treat to target in ulcerative colitis. However, it is also just as equally applicable to Crohn's and any form of inflammatory bowel disease in terms of the concepts of treat to target at least. But there's an animation there and algorithms. It's also a site for clinicians to go to as well, and it has algorithms and evidence-based articles that explain treat to target and how often to check. So I think education and spreading that knowledge is important.

Dr Neil Nandi (27:29):

So, clinicians and patients should also know this. One of the reasons, if you haven't heard about treat to target or this concept, is because in the last few years, it was harder for your physician to get some of these tests done, the Calprotectin specifically. And even something else I didn't mention, which is therapeutic drug monitoring, monitoring drug levels for certain biologic agents. And that's a whole nother topic there. But now coverage is better. It's not perfect, but

there's better insurance coverage, better ways to get this. So some of the financial obstacles for many patients, more than before, are removed.

Dr Neil Nandi (28:10):

So if you have to know, every time you go to your doc, you should always have a good understanding of, when's your next scope due? How often do you need a scope? And then the next question is, how do I know, if I'm feeling well, how does my doctor know, and how do I know that I am in remission in that time? And the reason for this question is that it is quite possible to have no symptoms, but to have active disease. And if you have no symptoms but active disease, that active disease is like an open wound or an open sore that you don't know is there and it can get infected. The analogy I use with my patients is like a paper cut. A paper cut looks nice and clean, hurts like a, bleep, but once... That's my sound effect. And if you rub that paper cut in some muck, it becomes all pus-filled and angry and red and boggy nasty.

Dr Neil Nandi (29:05):

So if you have a paper cut and out of this erosion or ulcer on the inside gut, that can get infected and you can flare and get C.diff, all sorts of bad things. So we want that to heal. And so another concept, this is how I also talk to my patients is, I want you to look as good on the inside as you feel on the outside. And now, hopefully, if you hear this by repetition to this podcast, if you're in remission, it depends on the doctor's style or the PA or nurse's style, whoever's treating you, but for a healthy patient, once or twice a year, blood work and maybe a stool calprotectin. As far as drug level monitoring, some clinicians are proactive, therapeutic drug-monitoring, others may not believe in it. And that's because the data, there's some controversy there.

Dr Neil Nandi (29:55):

I personally am a proactive therapeutic drug-monitoring proponent. So depending on the drug, I will check the level once or twice year in a healthy patient. Now, if you're flaring or you're not doing well, then at a minimum, you're probably going to get blood work, stool calprotectin two to three times a year, if not four times a year and more, whatever it takes to actively see that you're getting better or getting worse. Now, another question is, how soon can you expect remission or a response? And that depends on the medicine being used. They take anywhere from three to 12 weeks to show a response. Big range, depending on the agent, and it depends on your biology and your flavor or type of Crohn's or ulcerative colitis or indeterminate colitis, and how long it takes to respond. So it can take time.

Dr Neil Nandi (30:52):

Now here's other thing to know. Let's say you feel better. You can feel better before the tissue has had time to heal, and this is called tissue lag. So, after you start a biologic or a small molecule therapy, I typically tell my patients, all right, we're going to do these non-invasive markers, blood, stool, every three to four months, and then six to nine months after you've started, assuming you're doing well and doing much better, we'll schedule another scope. It could be a flexor, it could be a full colonoscopy, to confirm that the tissue looks as good as the

numbers and you clinically suggest. So that's a little bit more detail as to how we treat the target strategies.

Dr Neil Nandi (31:37):

So education, spread the knowledge, know this, and ask your doctor, ask your doctor, Hey, I read about this and some guy named Dr. Neil and Jacklyn... I'm going to drag you into the partner in crime, and Amber, started talking about this, and I want this doctor. I want my stool calprotectin, and I want my markers, and I think that I should get a scope six to nine months after I've started treatment.

Jacklyn Green (32:02):

Yes, Can we clone you? Can you be everyone's doctor? Oh, man. Or at least train-

Dr Neil Nandi (32:09):

Guess what, you asked for it.

Jacklyn Green (32:10):

... all the other doctors?

Amber Tresca (32:12):

I know, train a bunch of them. I'm old enough to remember that... I want my MTV, so I love this. I want my fecal calprotectin. So let's get that done. So, Jacklyn, how about you? Do you have any advice if new patients are thinking about, well, I've never heard of this treat to target. You had a really strong relationship with your team and you had really clear goals. How would you advise someone on how to begin that conversation and keep, keep these goals moving?

Jacklyn Green (32:43):

Well, I have a great strong team now, but I didn't initially. It took a while to get there and you have to speak up for yourself. You have to remember that this is your body and it deserves to be treated well, and it deserves to have a life. It's yours. It's you. So you need to ask the questions. My advice for talking to your doctor would be to remember that your doctor is your partner. They want you to heal. They are on this journey with you, and if you don't feel like they are, tell them that. If you're not feeling heard or respected, then I would say, say so, because you should.

Jacklyn Green (33:28):

And if you're still feeling that way after you've had that conversation, then go higher. Talk to the supervisor of the clinic, keep going until you find someone who will listen to you. You have to be the squeaky wheel. If you want to get that treatment, you have to use your voice and you have to be the squeaky wheel if they're not listening. Now, if we can clone Dr. Nandi and everyone can be like him, it would be great. And they would listen and you can have a conversation. But I think the first step is to ask how they want to communicate. I know with my

doctor, it's a lot through the portal. We do a lot of communication through the patient portal, and that's the easiest way to reach her.

Jacklyn Green (34:07):

I can send her a message and my other doctor can see it too. So I can say, this is what's going on. I need to come in, blah, blah, blah. Some doctors prefer that you contact their nurse. Some prefer that you call and leave a message and they'll call you back. There's lots of different ways of communication. The first office that I visited when I had UC, I would hold for two hours before I could get in touch with someone. And I didn't know any better on how to reach people. When I was first diagnosed, I was brand new to being a patient in general, and there was a lot to learn. But you have to take an active role, and you tell them at the appointment, I waited for two hours. What's a better way to communicate with you? Is there a better way? And if there's not, maybe you find another doctor. If there is, then let's do that.

Jacklyn Green (34:59):

Finally, I would say, for yourself, when you're making the goals, be honest, and then you have to keep those appointments and take the medication, follow the plan. If there's a problem, bring it up. You can't just assume that the doctor knows, or that they've seen your labs and know exactly what's going on with you. Because like you said, you could be appearing great on the outside and completely different on the inside or vice versa. Maybe you're not where you want to be. So, yeah, I just think you really have to use your voice and speak up for your body or, who else is going to do it?

[MUSIC: About IBD Serene]

Amber Tresca (35:59):

Dr. Nandi, I was on your Instagram and I saw that you shared that you have an interest in medical history. So I was just wondering, is there anything that you can talk about, about the history of gastroenterology that you have found in your studies or your research or your hobby, that was bizarre or odd or funny?

Dr Neil Nandi (36:24):

Yeah, lots actually. All right. I'll pick one. That's IBD relevant, okay?

Amber Tresca (36:35):

Nice.

Dr Neil Nandi (36:35):

But I have a ton. I have a ton of stuff that I could share, but... They always talk about ulcerative colitis and tobacco smoke, tobacco being protective, but it's only protective for about 70% of UC patients. If you're a UC patient and you're listening to this, do not pick up a pack of cigarettes because the Surgeon General warns that tobacco may lead to sudden death,

[inaudible 00:36:57]. Car, stroke, heart attack, cancer. And because it's harder to motivate men than women, erectile dysfunction. That's the only way I can get my men to stop smoking. So don't smoke. But tobacco can be protective.

Dr Neil Nandi (37:13):

In fact, when people quit tobacco, sometimes the classic story is, a female in their or 40s who quit smoking, and then six to 12 months later has [inaudible 00:37:22] and is diagnosed with UC. That's a broad question. But we don't recommend it because it doesn't help everybody. But 30% will have no response. So that's the background, right? So tobacco and that. Now how do you think we started to study this? Somebody tried to data mine this and be like, oh my God, we got to figure out how we can make some money off this thing. So what they did was, they took mice, poor little mice, nude mice. They actually shaved them down and they drink these nude mice. No, they're actually genetically bred not to have hair, which maybe even more cruel.

Amber Tresca (37:55):

You got me with that. You got me.

Dr Neil Nandi (37:57):

The scientific model for studying colitis is a mirroring model where they drink water, DSS model. It's an acid, and that's horrible because they're drinking acid water, and you give medicines to the mice and you see if their intestine heals. That's the basics of it. So they took the tar from tobacco, cigarettes, and they rub it on the skin in and it's transdermally absorbed. And guess what? The colitis gets better. Yeah. And then they thought, well, how else can we take this a step farther? I think they were saying, can we cross the line? And they said, can we give these poor little mice that we've induced colitis in, can we give them tobacco smoke enemas? And they did, and they get better.

Dr Neil Nandi (38:43):

Now, I would not want to be the lab technician literally blowing little tobacco smoke into the anuses of these poor mice. But you get the visual.

Amber Tresca (38:54):

That [inaudible 00:38:54] on floor.

Dr Neil Nandi (38:55):

But bottom line, they could not ever isolate because, going back a couple decades ago, what the magic molecules or combination of molecules that was protective to induce remission in UC patients? And so it's still a medical mystery. We still again do not endorse tobacco smoke for UC and again for Crohn's patients that makes Crohn's worse. So don't do that. So many reason not to smoke. But I think that's some interesting medical history, some crazy medical experiments that have been done that I've been the one to look up and read out of fascination, perverse

fascination, perhaps. But this is what the... I couldn't make this up though, tobacco smoke enemas. Interesting.

Jacklyn Green (39:31):

Yeah. That's a stop-blowing-smoke situation there.

Dr Neil Nandi (39:35):

[inaudible 00:39:35].

Amber Tresca (39:35):

And when I was diagnosed and I was diagnosed the way, way long ago of 1989, there was more than one person that offered me a cigarette. So it was one of those... There was some truth to it, but it was also like an old wife's tale type of thing, that people would say, oh, you have colitis? Well, maybe you should take up smoking, but I never did do that.

Dr Neil Nandi (40:03):

Good, good choice.

Jacklyn Green (40:03):

I was told to.

Dr Neil Nandi (40:04):

Were you?

Amber Tresca (40:06):

You were told to smoke too?

Jacklyn Green (40:07):

Yeah.

Dr Neil Nandi (40:08):

By a physician?

Amber Tresca (40:09):

And you were not diagnosed that long ago.

Jacklyn Green (40:10):

Yes. Yeah, that was 2018. Yeah.

Amber Tresca (40:12):

Wait. Who told you to smoke?

Jacklyn Green (40:16):
My GI, my first GI.

Amber Tresca (40:17):
Stop.

Jacklyn Green (40:17):
It was the PA at the GI's office. Yeah. That's…

Dr Neil Nandi (40:22):
This podcast does not capture my mouth, my jaw dropping to the floor.

Jacklyn Green (40:26):
You did it to me with that mouse story. So I got-

Dr Neil Nandi (40:27):
You got me back, Jacklyn.

Amber Tresca (40:33):
Your jaw unhinged there.

Jacklyn Green (40:35):
It was sad.

Amber Tresca (40:35):
Just like, oh.

Jacklyn Green (40:37):
Yeah.

Dr Neil Nandi (40:37):
The good news is that if you do need medicines, they don't carry those types of known and higher risk by the way, higher known multitude risk factors of stroke, heart attack cancer, et cetera. So, that's the good thing about some of the medicines that we have.

Jacklyn Green (40:52):
Yeah.

Amber Tresca (40:53):
Oh, my gosh. So Jacklyn, that a funny story, not funny at the time, but we're laughing about it now.

Jacklyn Green (41:00):

Right.

Amber Tresca (41:01):

Do you have any other funny or embarrassing stories that you can share?

Jacklyn Green (41:05):

I do. I do. I thought of one actually, while we were talking about this and talking about the stool samples. So I think I'm going to go with that one. I was doing my very first stool sample where I had to go pick up the kit, take it home and bring it back to the lab. And the lab that I was going with is at the main hospital in our area. And so I did the thing, take it home and bring it back to the hospital. I'm parked out front, I'm carrying it inside. And the lab is in there. So I'm walking in and I bump literally into my high school crush and his wife.

Jacklyn Green (41:54):

And they proceed to catch me up on their life for the last 10 years as I'm standing there holding literally poop in my hand, in a big white bag going, oh, my gosh, is this really happening? Get me to the lab. How can I get out of this? So, that was probably one of the most embarrassing moments. They never asked what was in the bag, but it's a big white bag and I think, you know... So, that was probably it.

Dr Neil Nandi (42:22):

In retrospect, that's a funny story though. Yeah.

Jacklyn Green (42:26):

Oh, absolutely.

Dr Neil Nandi (42:26):

Yeah.

Jacklyn Green (42:26):

I think I still laughed when I got back to my car, like, was that real? But-

Dr Neil Nandi (42:30):

That's like out of a Ben Stiller movie or something. I don't know. So I can see that. Yeah.

[MUSIC: IBD Dance Party]

Amber Tresca (42:37):

Yeah. Jacklyn Green, Dr. Neil Nandi, thank you so much for coming on about IBD and talking with me about treat to target. I really appreciate your time and everything that you shared, especially the mouse stories. That is fantastic. So, thank you so much.

Dr Neil Nandi (42:52):

I aim to please. There you go. Show me the line, I'll cross it. Okay. Thanks for having us.

Jacklyn Green (42:58):

This is great. Thank you so much. Both of you.

Amber Tresca (43:03):
Hey super listener! Thanks to Dr Neil Nandi for sharing his knowledge and perspective to this topic and for all he does in teaching both patients and clinicians. You can follow him across social media as FitWitMD, which stands for Fitness Witness.

Thank you also to Jacklyn Green for sharing her journey with us, including the difficult parts. It's easy for me to ask the questions; but Jacklyn had to relive some of the worst times in her life to answer them. Thank you for the gift of your story, Jacklyn, it will help so many in the IBD community. You can follow Jacklyn on Instagram as JacklynHopes.

Amber Tresca (43:41):
Links to a written transcript, everyone's social media handles, and more information on the topics we discussed is in the show notes and on my Episode 109 page on AboutIBD.com.
You can follow me across all social media as AboutIBD.

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

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