

[00:04:07] **Dr. Laurie Keefer:** So I really became interested in resilience in the inflammatory bowel disease population because I was seeing patients clinically in practice and I would see many of whom are young at the time of diagnosis. And the diagnosis of Crohn's or ulcerative colitis often can happen in late teen years, early young adulthood.

[00:04:29] And so for many patients, this is the first time something bad has happened to them. And so, they are really faced with this opportunity, challenge, if you will, to have to rise to the occasion of a diagnosis. And so, while I would see some patients with very severe disease present and take it in stride and still go on to, you know, go away to college or, go on to have children, I would see other patients who had very mild disease, if you will, but who just couldn't find a way to move on from the devastation of the diagnosis.

[00:05:06] And so my research questions really stemmed from that clinical experience, asking, what strengths do people have that they're equipped with to be able to move on and potentially even thrive despite this very serious condition.

[00:05:22] **Stephen Calabria:** And what does that look like?

[00:05:24] **Dr. Laurie Keefer:** So we've actually homed in, over the last 20 years or so, my research has focused on what we call now the Resilience 5.

[00:05:31] These are our targets in all of our interventions at the IBD Center at Mount Sinai. Those are, the ability to accept your disease. I always say you don't have to approve that the diagnosis happened, but you do have to accept that it's happening to you and that you have to be able to address it.

[00:05:48] You have to have learned optimism, not looking at the problems in your life as personal, pervasive, or permanent, but rather really kind of learning a way to attribute positive and negative events in a much more optimistic way. Not stupid optimism, but learned optimism.

[00:06:06] The third is self-regulatory skill. Self-regulation means being able to calm yourself down and persist despite frustrations and obstacles. You need self-confidence and the ability to manage your disease. So, for example, do you know how to swallow pills, can you inject yourself, can you follow a diet recommendation, can you do a colonoscopy prep, do you actually have those skills?

[00:06:28] **And then the last and maybe one of the most important, other than acceptance, is social support and having that network and community of people, role models, that you can really rely on for a lifetime.**

[00:06:42] **Stephen Calabria:** So you've talked about how so many of your patients, a disproportionate number of your patients are young adults, teenagers, preteens. Because this can be such an all-consuming health problem, particularly for a young person, how do you approach that first conversation with them regarding their illness?

[00:07:02] **Dr. Laurie Keefer:** There are several different approaches depending on the age, how involved the parents are. But, we really try to present the diagnosis and all of the demands as, as attainable, as bite- size.

[00:07:18] We try to break it down. People are often very overwhelmed when they're diagnosed. And so we really try to prioritize what needs to happen first, second, and third. I do a lot of talking about, "cross that bridge when you come to it." "Let's not get ahead of ourselves." You know, "eat the elephant one bite at a time"-kind of scenario.

[00:07:36] I think it's also really important that we as providers convey optimism. It is, you know, there are treatments available, um, there's no cure, but there are a lot of different ways that you can work with your doctor to live a perfectly normal life. And so we really do try to, to lead with optimism, with hop. A lot of humor, as well.

[00:07:58] I, I think there's so much stigma attached to gastrointestinal conditions and bowel movements that really being able to laugh a little bit about it, to talk about the things that people don't normally talk about in conversation can really improve the acceptance of the condition.

[00:08:14] **Stephen Calabria:** Talk about that a little bit. The role of humor in helping someone accept a horrible situation. Is that something that comes up with your patients pretty frequently?

[00:08:24] **Dr. Laurie Keefer:** All the time. One of the reasons I love working with gastroenterologists is that they're a funny kind of doctor. And I think my humor kind of fits with that as well, and we'd really try to translate that to the patients.

[00:08:38] And, you know, there's some, a lot of really unfortunate symptoms that patients will have or they'll be afraid of having, incontinence being one of them. And while these can be quite catastrophic events, sometimes being able to tell funny stories after they've happened or to, kind of share the stories of other patients, worst-case scenarios, for example, can be really helpful.

[00:09:01] For example, I have one patient who still probably has the funniest, most horrible, worst- case scenario ever. She's still, when I see her periodically, she'll still ask, has anyone topped it yet? And that involved her, basically, deciding to travel despite terrible ulcerative colitis symptoms. She was in a park, outdoor park in Paris, France, and had to go to the bathroom and couldn't make it and was running for Porta-Potty that they have in the parks to be able to clean herself up a little bit. And she was crying and she was upset, of course, and, unfortunately, what she didn't realize is that President Macron was coming to talk there the next day.

[00:09:46] And so, Secret Service, or the equivalent of that , happened to be paying close attention to how long people were in the Porta-Potties on the lawn. And so, unfortunately, um, while she was cleaning herself up, heard this knock on the door, "open up, police, come out,"

[00:10:01] And, you know, really, that's everyone's worst case scenario. I think it's pretty much whether you have ulcerative colitis or not, but we still kind of laugh about that story.

[00:10:11] **Stephen Calabria:** You touched upon acceptance as being one of your resilience pillars that you teach your, your patients. The ability to meet challenges head-on and deal with the consequences. Do you often find patients and their families find this diagnosis or the, this series of diagnoses to be particularly difficult to face?

[00:10:34] **Dr. Laurie Keefer:** Absolutely. I think that avoidance is a very natural experience, right? Something bad is about to happen, or you don't want something bad to happen, so you'll avoid.

[00:10:44] And we've really tried, while it may make sense to avoid things, in the long run, it doesn't teach confidence. And again, because we're talking about a lot of young people, for example, parents will often say, we want to get my child extra

time on tests, right? I want my child to not have to take the bus to school. They need their own parking space.

[00:11:08] And while I certainly get that as a parent, it's really important that we signal to the children and to the young adults that they can do these things. They might have to accommodate them. They might have to have a different mindset. But avoiding actually just makes you more anxious.

[00:11:28] Avoiding actually tells you, tells your brain that you shouldn't do something, that it's scary or something to be afraid of. And so, to the extent we can, we really try to push our patients to face their fears, to have the courage, to try things despite worst-case scenarios potentially happening, you're always taking that risk.

[00:11:50] Most of the time they don't, and that builds self confidence, and really sets you up for life in general.

[00:11:55] **Stephen Calabria:** The problem, I imagine, or one of the many problems that arises is that this is difficult enough of a diagnosis to experience when you're an adult. When you are a child, a young adult, having to contend with other merciless children, it is, I imagine, exceedingly difficult. How do you convey that to a child, that they have to power through this, when they know they might be walking into a firing squad when they go to school the next day?

[00:12:31] **Dr. Laurie Keefer:** Yeah, we definitely see a fair amount of that. You know, um, one of the symptoms of, of childhood pediatric onset Crohn's disease, for example, is failure to thrive, failure to hit puberty at a normal rate, failure to grow, right?

[00:12:46] And so that is a recipe for getting picked on, especially for the, our boys, and it's all part of that wanting to avoid school, wanting to avoid certain classes, wanting to avoid the bathroom at school. And, you know, we really do have to ask our patients to override things.

[00:13:02] We have to get them to figure out what their superpowers are to be able to override, um, some of those merciless, um, situations. So, you know, we do require all of our patients to have an elevator pitch ready for what their disease is, how it affects them, to whatever extent that is comfortable or makes sense.

[00:13:21] And that can really empower patients, because they can kind of make sure that they have thought through how they want to confront somebody. So we're happy to do sort of social skills training, helping people stand up to, to the bullying. We can do accommodations, get the teachers involved, school nurses involved, but absolutely.

[00:13:42] It can be really difficult, even for college students on the dating scene or what do they do if they go to a fraternity party and want to drink alcohol? How do they fake that they're drinking so that people don't come up and ask them why they're not? You know, a lot of that requires a fair amount of skill that we have to teach our patients.

[00:13:59] **Stephen Calabria:** Folks who don't have this diagnosis have a picture in their mind of what it might look like, a lot of the challenges that arrive. What are some misconceptions about ulcerative colitis, and how do you see this impacting each patient's sense of hope for the future?

[00:14:17] **Dr. Laurie Keefer:** That's a great question. I think that, um, one of the misconceptions that many patients struggle with as well, because they hear it from, from other people and they hear it from TV, is that stress, diet, lifestyle, somehow caused the condition, right? That it's their fault and if they had just been healthier or they hadn't gotten themselves so worked up that they would, not have this condition.

[00:14:41] And so many patients will come in with a sense of shame or a sense of guilt, for having done something or some indiscretion that might have caused it. And we have to sort of break that down and say, you know, certainly the gut interacts with the environment, and certainly there are environmental things that make it worse.

[00:14:59] Stress never helped anything get better, certainly. But that really these are genetic disorders that are turned on by some hit or injury and happens to be at the age you're at, and it's when you were going to get it, and trying to give yourself that grace that you didn't cause this can be really important.

[00:15:19] **Stephen Calabria:** It's difficult enough as a patient to deal with those feelings of guilt and shame. As a parent, I cannot even imagine what these folks are going through.

[00:15:29] **Dr. Laurie Keefer:** Yeah. Absolutely. Watching your child get this chronic diagnosis.

[00:15:32] **Stephen Calabria:** That's genetic.

[00:15:33] **Dr. Laurie Keefer:** That's genetic. Right. So parents often will, where did it come from, it can create conflict in families. You know, your side of the family had the GI problem. I think it can also, you know, many times kids will complain of gastro symptoms, abdominal pain, nausea, those are common emotional symptoms that kids have. So a lot of parents will say, I dismissed them, or I took the kid to the pediatrician and he said it was just stress or they didn't want to go to school.

[00:15:59] And so, many times there's a delay in diagnosis, particularly in Crohn's disease, which is more common in children. And the parents feel a lot of guilt around that and try to make up for it by, you know, sort of snowplowing the rest of the way through their child's life.

[00:16:15] **Stephen Calabria:** It's exacerbated by stress. Is that right?

[00:16:17] **Dr. Laurie Keefer:** Absolutely.

[00:16:18] **Stephen Calabria:** And so the effects of the illness are compounded when you add in the social factors and the family factors that you just touched upon. There is perhaps no greater aspect of resilience in many cases than social support. You even touched upon it in, in your five.

[00:16:36] The idea that someone out there has our back, especially if it's someone we love, who loves us. Talk a little bit about that. You, you accentuated social support as being really important to convey to, to patients.

[00:16:48] **Dr. Laurie Keefer:** Yes, I mean, I think, first of all, this disease is, can be very isolating. Um, a lot of people don't understand what the digestive tract does or doesn't do. And so even when you tell somebody you have a digestive disorder, it doesn't always make sense to them as to what you're actually dealing with. I think things like fatigue make it hard for you to engage with other people because you're sort of picking and choosing what social events you want to go to.

[00:17:12] So having people who understand why you might cancel at the last minute or why you might be too tired to stay out for that extra ice cream cone after the movie. All of that, you know, really kind of challenges the social support system. So having people in your corner can be really helpful. I think, you know, if I can, there is a great example in the science around these little monkeys called cotton-top tamarins.

[00:17:39] These monkeys are about a foot tall and they are genetically predisposed to developing ulcerative colitis in captivity. So when they live in the wild, they don't develop it, but when researchers go and take them from their habitat and put them in cages, they go on to develop bloody diarrhea.

[00:17:57] And when they return them back to the wild, that diarrhea in the blood goes away. And initially, they thought it was the stress of captivity. This was a research done in the 1950s. They thought it was the stress of being in cages that triggered that and it's not to say that that wasn't partly true, but after sort of manipulating other factors, diet and altitude, and cold and temperature.

[00:18:23] What they realized is that, the stress of having, being in captivity, sure, was triggering, but actually cotton-top tamarins live in groups of three, not in groups of two. And the researchers had put them in twos, in pairs, in the cage, thinking that was sufficient for their social support structure, but their support structure was missing a tamarin.

[00:18:44] So, once they sort of recovered from that, the tamarins were much better able to adjust from the stress. And so what we always talk about at the IBD Center, asking patients, find your Tamarins. Who are your Tamarins? One, two, you know, three. Who are the, who's the, you know, two other people that you can count on when you're stressed?

[00:19:03] Because social support is always important, but particularly when you're undergoing stress, it can really buffer the impact it has on the body physically.

[00:19:14] **Stephen Calabria:** Folks who have gone through something tough in their lives often emerge from the experience with a greater sense of meaning and purpose, as though it reminded them of what was really important. Have you often found that with your patients, that they emerge from this perhaps better off?

[00:19:30] **Dr. Laurie Keefer:** Absolutely. I mean, I think it's hard to see that when you're starting out, but so many of our patients end up going into something related to inflammatory bowel disease. We have patients who become doctors, patients who become disability advocates, patients who become volunteers in the field because they want to give back and they feel that part of the community.

[00:19:55] And I think that really is important. Many patients will say, you know what? I have more empathy than I ever thought I would have, because of this illness. I'm stronger than I ever thought I could be. I stopped sweating the small stuff, right? I stopped caring so much about every single paper I wrote and just being grateful that I have my health.

[00:20:16] And I think that is all part of that meaning and purpose in life and, and really grounding you in, in what's important.

[00:20:23] **Stephen Calabria:** You've also talked about the unique role that Mount Sinai has played in this area, not just historically, but with regard to the original research that's coming out of Sinai. Could you talk a little bit about that?

[00:20:35] **Dr. Laurie Keefer:** Yeah, absolutely. So, right, so historically, Crohn's was discovered here, so we take a lot of pride in that but, from a resilience perspective, obviously Sinai is very much a well-known resilience institution. Lots of research comes out of here in resilience, but what we did in, in the IBD center was really kind of take a lot of those resilience concepts and really for the first time apply them to a chronic disease state, right?

[00:20:59] So a lot of resilience research in the past has been focused on post-traumatic stress, prisoners of war, anxiety and depression, but to take it and actually apply it to a brain-gut disorder, because of the physiology of resilience as well as the psychology of resilience really is really important is, is critical to, to managing Crohn's and colitis.

[00:21:18] And so what we did was we developed a methodology that could be delivered to the 12, 000 IBD patients at our center, to be able to assess their resilience, prioritize which targets of those resilience five targets needed the most intervention or tweaking and which ones didn't, and then developed a care plan.

[00:21:39] And then followed patients over time, intervening as we saw fit. So from 2016 to 2020, we followed a cohort of over almost 200 patients, and

compared them to a cohort of 200 patients who didn't get our method and we were able to show that we substantially reduced unplanned healthcare utilization.

[00:22:01] So, emergency department visits, surgeries, hospitalizations, opioid use, steroid use, in the patients who receive that Resilience 5 training. And in fact, now we're looking to be able to start seeing whether, if you combine a new medication, a biologic medication, and resilience training up front, do you improve outcomes over the long term? And that's something that we're looking at right now at Sinai, as well.

[00:22:28] The word resilience is a very scientific word and it's something that's been in the scientific community for, for many, many years, but, you since COVID and, and, you know, I think people throw the term resilience around a lot without really understanding that, you know, what that means.

[00:22:45] And so, you know, some of my patients will say, you know, I don't, I don't like the word resilient because I don't have an option. I of course, I have to be, you know, it's not like I chose this. I've had patients say, I don't like the term self-management because like, why should I have to manage this condition, right?

[00:23:03] Why can't the system manage it? I think people say, you know, I'm not resilient or I shouldn't have to be resilient. The medical system is traumatic and I wouldn't have to be resilient if it wasn't. So you know, I think it is really important to talk to patients about resilience in a more scientific way.

[00:23:21] To make sure they understand that when we throw that word around, we're talking about specific skills and mindsets that allow the body and the mind to bounce back from adversity, and not even just to bounce back, but to bounce forward, further, and that is both biological in terms of your immune system, in terms of your autonomic nervous system, as well as your ability to grow from experiences.

[00:23:48] But, yeah, it can be very difficult sometimes, to just throw the word resilience out there without really understanding the science behind it.

[00:23:56] **Stephen Calabria:** Right. And, I imagine some patients may find it a hokey term, that, that, oh, I'm so resilient. No, like that's an embarrassing thing to, to say about oneself, but, you're speaking in more of a clinical or scientific way.

[00:24:12] **Dr. Laurie Keefer:** Yeah, exactly, I mean, I say, you know, bridges are resilient, right? We build bridges with the idea that there could be wind or water underneath them that affects, you know, the structure and when it needs some room to give.

[00:24:25] And so, these are engineering terms. They're not just psychological terms, but I, I do think unfortunately, you know, many patients will say, I guess I'm just not resilient because I'm struggling. And, you know, it's, we, we always try to say everyone's resilient. Everyone starts out resilient.

[00:24:41] Resilience comes with time and experience, and maybe you just haven't had enough bad things happen to you yet, and if we can, you know, increase your resilience earlier on so that you can bounce further, you can flourish in life, by teaching you some things that we've learned from our other patients along the way, why not give that to you earlier on?

[00:25:04] **Stephen Calabria:** And because so many of your patients are younger, they haven't even had the chance yet to develop those resilience skills.

[00:25:11] **Dr. Laurie Keefer:** That's right, exactly. And all we're doing is just helping them. move forward and giving, you know, telling them, Hey, we've seen a hundred patients before you. We're going to see a hundred patients after you, but the same problem.

[00:25:22] Let's take what we're learning from all these people, what coping strategies work for them, what things we should be looking for and apply it to you. You don't have to walk around with your hand behind your back. We can help you. We know what to do. And that's the optimistic component is this might be terrible for you. But many people have gone before you and thrived.

[00:25:42] **Stephen Calabria:** And I imagine that is also helpful to patients, particularly young patients who, they may feel overwhelmed by this, they have never met someone else who had this before. They may be thinking to themselves, this is a problem with me and only me that I have to overcome. So it's probably helpful to them to know that there are so many others out there.

[00:26:03] **Dr. Laurie Keefer:** Absolutely. And you know, there are famous role models out in the community that talk about living with ulcerative colitis or

Crohn's disease. I think people are talking more about mental health impact of these diseases, again.

[00:26:18] And then even just connecting patients. We will, you know, carefully, of course, and, and very thoughtfully, we will introduce patients to each other or we'll introduce parents to each other, especially if somebody's about to have a surgery and the parent wants to kind of know, what should I expect from my kid or somebody just got out of the hospital and, you know, wants to kind of talk to someone else that had a similar hospitalization experience.

[00:26:44] Anything we can do to mitigate the trauma of, of disease and get people to talk about it and share their experiences, we know that that improves and reduces the risk of post-traumatic stress. So all of those things are really important.

[00:26:58] **Stephen Calabria:** Is that a big factor?

[00:27:00] **Dr. Laurie Keefer:** Post traumatic stress?

[00:27:01] **Stephen Calabria:** Yeah.

[00:27:01] **Dr. Laurie Keefer:** So, yeah, so the data is now coming out really showing that up to 30% of patients with IBD experience medical trauma and potentially symptoms, if not the actual syndrome, of post traumatic stress. And the problem that's a little bit different from more traditional traumas like a gunshot wound or a sexual assault or something like that, natural disaster, is that our patients have to live in the bodies that are traumatized. And so they're re traumatized all the time. They can't avoid it.

[00:27:34] They can't escape it. They have to go into the traumatic environment, right? They, if they had a trauma in the hospital, they can't avoid going to the hospital again. If their trauma was during a procedure, a colonoscopy, they still have to go in for the colonoscopy. So, so for us, you know, really trying to decrease, recognizing that the traumas are always happening, but to decrease the avoidance behavior, to decrease the interpretation of them as traumatic, knowing that they have to live in that body, and knowing that even at a cellular level, their bodies remember, pain at the site of a surgery, and that never really leaves them, we, we definitely try to do very much a trauma informed care.

[00:28:24] **Stephen Calabria:** So conceivably patients in virtually any area where they were to receive this resilience training might receive better outcomes.

[00:28:33] **Dr. Laurie Keefer:** Absolutely. That's what we think. And actually, that is partly why Mount Sinai helped gastroenterologist Marla Dubinsky, um, and I co- found a spinoff company called Trellis Health, that basically takes that methodology that we invented and refined here at Mount Sinai, licensed it to Trellis Health and allowing it to commercialize, scale it, digitize what's possible, and then still provide that human touch so that literally you don't have to be at Mount Sinai.

[00:29:03] We can take our method and put it out into the community at practices that don't have this level of service for, for their patients. And so that's another sort of unique thing about Mount Sinai's program, is that they had that innovation piece of it. You know, we worked with Mount Sinai Innovation Partners, to really be able to commercialize this method.

[00:29:24] **Stephen Calabria:** We've spoken about this before, about your work, and you shared a patient story that I found really touching about a little girl. Do you recall that? Could you, could you tell that story?

[00:29:35] **Dr. Laurie Keefer:** Yeah, so I see a lot of young patients, as I mentioned, I, there was a particular patient that really kind of tugged at my heartstrings because her parents didn't really want her to go on a biologic medication, even though that was indicated, and try to manage her disease primarily through diet. A very restrictive diet, actually called the specific carbohydrate diet.

[00:29:58] **Stephen Calabria:** Was this for religious reasons?

[00:30:00] **Dr. Laurie Keefer:** For religious reasons, yeah. Although not necessarily all religious reasons. I think there were other factors. But certainly for religious reasons.

[00:30:08] And, sort of an orthodox Jewish family, which we see a lot of in, a lot of IBD in that community in particular. So, you know, we're very sensitive to that. But, um, over time, you know, as this woman, this girl became a woman, she, you know, really wanted to be able to feel better, to not be so restrictive in her diet, and particularly to be able to get pregnant.

[00:30:32] And the inflammation in her body would have prohibited a lot of those goals. She really did need to escalate. And so working with her, getting her to kind of be able to make her own medical decisions, you know, appreciating some of the nuances of, of her religion and her faith, but also how this medication could also achieve some of the other goals related to her religion and her faith.

[00:30:57] She finally kind of went on a very effective medication and now has a, has a, I guess a three-month-old son to show for it. And it's just one of those really nice stories where you can sort of work with patients and their families and watch them, sort of, come out on the other end and achieve the goals that they had for themselves.

[00:31:15] **Stephen Calabria:** Well, that was it for my questions. Was there anything else you wanted to say?

[00:31:21] **Dr. Laurie Keefer:** No, and this was, this is great. I could talk about resilience, in IBD all, all day. I think that, you know, a lot of what I talked about today probably, you know, obviously my passion is in Crohn's and Colitis, inflammatory bowel diseases but I think a lot of it applies to other chronic conditions that we see here at Mount Sinai as well. So, it'd be interesting to see, , you know, who else you encounter along the way around chronic disease and resilience.

[00:31:47] **Stephen Calabria:** Dr. Laurie Keefer, thank you so much for coming on the show.

[00:31:49] **Dr. Laurie Keefer:** Thanks for having me.

[00:31:51] **Stephen Calabria:** Dr. Laurie Keefer is the Director of Psychobehavioral Research within Mount Sinai's Division of Gastroenterology. That's all for this episode of Road to Resilience. If you enjoyed it, please rate, review, and subscribe to our podcast on your favorite podcast platform. This podcast is a production of the Mount Sinai Health System. It's produced by me, Stephen Calabria, and our Executive Producer, Lucia Lee. From all of us here at Mount Sinai, thanks for listening and we'll catch you next time.