

About IBD Episode 95

Kelly Owens: Vagus Nerve Girl

What is the next innovation in the treatment of inflammatory bowel disease (IBD)? Is it the microbiome? Stem cells? Or, is it the emerging field of bioelectric medicine?

IBD is a complicated disease to treat and can bring complications and other, related conditions. The problem is the immune-mediated nature of the disease and how it affects the entire body. For Kelly Owens, who lives with Crohn's disease, bioelectric medicine has bumped her into remission and changed her life in several ways. Today she goes by "Vagus Nerve Girl" because she had a device implanted in her chest that stimulates her vagus nerve. For her, this treatment has been a resounding success.

Concepts discussed in this episode:

- [TED Talk: How electricity could replace your medications - Neurosurgeon Kevin Tracey](#)
- [Osteoporosis](#)
- [Discovery and Functions of Acetylcholine](#)
- [Anatomy of the Vagus Nerve](#)
- [What Is Vagus Nerve Stimulation \(VNS\)?](#)

Find Kelly Owens on [Twitter](#), [Facebook](#), and [Instagram](#) and on her blog, [Vagus Nerve Girl](#).

Find Amber J Tresca at [AboutIBD.com](#), [Verywell](#), [Facebook](#), [Twitter](#), [Pinterest](#), and [Instagram](#).

Credits: Mix and sound design is by [Mac Cooney](#). Theme music, "[IBD Dance Party](#)," is from [Cooney Studio](#).

[MUSIC: About IBD Theme]

Amber Tresca 0:04

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

Welcome to Episode 95.

IBD is a complicated disease to treat. Years ago there were few medical options but the past 20 years has seen the approval of several medications with different mechanisms of action. More recently we're seeing a focus that's moving away from medications such as small molecules and biologics and into other potential treatments such as manipulating the microbiome or stem cells.

That brings me to my guest, Kelly Owens, who is maybe better known as Vagus Nerve Girl. Kelly lives with Crohn's disease and inflammatory arthritis. When she ran out of medical options, she gambled everything to move to Europe to take part in a clinical trial.

She had a device implanted that stimulates her vagus nerve. For her, this treatment has been a resounding success. Since achieving remission she has been a champion for bioelectric medicine and now works with the physicians who are pioneering the field.

Kelly and I met a few years ago at a conference that explored innovations in IBD treatment, including bioelectric medicine. It's my pleasure to introduce her to you so you can hear her incredible story.

Amber Tresca 1:23

Kelly, thank you so much for coming on about IBD

Kelly Owens 1:26

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

Amber Tresca 1:30

It's been a while since we've been able to talk or Gosh, it's been quite some time since we've seen each other...

Kelly Owens 1:37

I know, it's probably what's it been maybe two years.

Amber Tresca 1:41

It is almost two years, I think.

Kelly Owens 1:43

Yeah, I know, too long.

Amber Tresca 1:46

It's just too long. We plan to get together, but then you know, scheduling and then pandemics. So Exactly.

Kelly Owens 1:52

Exactly. Life in the time of Corona.

Amber Tresca 1:55

Exactly. But you know, we're together now. So that's great, at least virtually. I want to talk to you today about your disease journey, because you have some really very novel ways that your disease has been treated, and I want to hear all about that. But first off, I wonder if you would tell me more about being diagnosed with Crohn's disease, because I think you were a teenager when you were diagnosed. Right?

Kelly Owens 2:17

Right. I was diagnosed at 13. And my disease came on, in a way I think, you know, what's interesting was that I, I twisted my ankle. I was in a play called The Music Man. And while I was practicing one day, I twisted my ankle. And you know, of course it swelled right up. And we thought okay, sprained ankle, but what happened after that was that the swelling just never went down.

Kelly Owens 2:42

And my orthopedist withdrew like 10 cc's of fluid out, and it filled back up that evening. And then within a matter of a couple of weeks, I started experiencing gastrointestinal symptoms, like diarrhea and nausea, and was excusing myself from class I was in eighth grade at the time, I had to leave, you know, 20 times a day to go to the bathroom.

Kelly Owens 3:07

And so when my orthopedist kind of strung this all together, he was like, Alright, I think we have more going on than a sprained ankle. And sure enough, they did a colonoscopy, an endoscopy, and I was diagnosed with Crohn's disease with extra intestinal manifestations of inflammatory arthritis. And I tested negative for the rheumatoid factor. So it was just a IBD, inflammatory arthritis, but that eventually spread to over the course of 15 years, spread from my ankle to every joint in my body. And so by the time I was 25, I just had inflammatory arthritis, from my jaw all the way down to my feet. And, you know, my feet determine from inflammation and, you know, I couldn't straighten out my arms from the inflammation in my elbows. And it was, it was a pretty, pretty miserable experience for a kid.

Amber Tresca 4:02

Would you say that the Crohn's disease was sort of almost secondary to the arthritis. That's what it sounds like.

Kelly Owens 4:08

The arthritis definitely was the main event for me for 15 years, the colitis would come on, during really intense periods of stress. So I, you know, and I never had a clean colonoscopy. But the arthritis was really my main issue and the colitis was really secondary. And, you know, the colonoscopies I think we counted them up over 15 years.

Kelly Owens 4:37

I think I I think they are maybe 17 years I had about I think 20 colonoscopies and you know, I so many patients with IBD can relate to that. You're just like, God just took me a break from these colonoscopies, but the but yeah, they, they never you know, there was always active disease and my colon you know, but the colitis really reared its head. It was at its worst in 2015. And before that, it would happen maybe twice a year I would have really bad bouts of flares. But you know, the inflammatory arthritis really was the the worst of the worst for me.

Amber Tresca 5:20

In a lot of cases the some of the treatments for Crohn's and then some of the treatments for arthritis are, are the same. What were you being treated with did anything work? Because it sounds like maybe nothing was really hitting the mark for you.

Kelly Owens 5:32

No, nothing really hit the mark. I was I you know, over the course of those, you know, 15 or 16 years I was on every biologic that was available up until 2017. So that was about 22 different biologics, DMRDs, and immunosuppressants, over 15 years, it was pretty intense, you know, the Remicade, Stelara, Humira, Cimzia, Enbrel, methotrexate, you know, you just the list just goes on and on and on. And, you know, they never, they never hit the mark.

Kelly Owens 6:02

For me, it was always a matter of us just trying to figure out what combination, whether we did Remicade with 6-MP or we added in prednisone. Prednisone was the constant throughout it all, which is why my bones are still recovering. But luckily, they are recovering.

Kelly Owens 6:19

So that's good, you know, but yeah, none of them, none of them gave me relief. And, you know, I always tell people that, because, you know, these, these drugs are so heavy, you know, like, and for so many people, you know, there have been, you know, people that have benefited from these drugs, and thank God, we have those drugs, while we bridge the gap to the next great thing, which we'll talk about, you know, after but, you know, for so many people like me, you not only end up then dealing with the disease symptoms, for me, I felt like a nuclear power plant, you know, and Shawn and I were actually looking at pictures yesterday, and I was telling him about how you can tell my pre vagus nerve stimulator life to my post, not only just from the inflammation in my face, but also my eyes were so glassy, you know, I think that immunosuppressives really, just they take over everything, you know, so it was, it was rough, you know, you had that, that feeling of Okay, I'm dealing with this disease. And now I feel like a radioactive nuclear power plant.

Amber Tresca 7:24

Yeah, I identify with that a little bit. There was not as many treatments available when I was diagnosed, but I kind of felt like that through all of the testing undergoing all of the colonoscopies. And when I was diagnosed, it was a lot of like, abdominal x rays. And it Yeah, it definitely just felt like you were under constant assault...

Kelly Owens 7:48

Yes.

Amber Tresca 7:48

...from all of these things, and I don't know how much of it was in my brain versus how much of it was actually in my body, but it almost doesn't matter. Because you just feel that way.

[MUSIC: About IBD Transition]

Amber Tresca 8:03

Your husband, Sean, so you guys made some big life choices to get you out from under all of this. Tell me what happened when you hit that wall as far as therapies were concerned? And what you did next?

Kelly Owens 8:15

Absolutely. So I always tell people thank the universe for Shawn. You know, he's a, he's remarkable. And we've been together since we were 17 years old, and have known each other since we were five. And so he really, he really doesn't remember me ever being healthy. You know, we were on the bus together before I got diagnosed. So he remembers me running up and down the aisles of the bus. And, you know, it was a crazy kid pre diagnosis. So I was, you know, jumping over bus seats and everything. So he remembers that. But um, you know, we it doesn't...

Amber Tresca 8:51

This doesn't surprise me, hearing that...

Kelly Owens 8:54

I know. Not at all.

Kelly Owens 8:57

So, Shawn remembers, you know, he remembers that part of my my life, but we became friends when I was 15. And after having known each other all those years, and so, he he really has only experienced intimately, my, my disease. And so, you know, when, throughout all those years, we were always just waiting for the next thing, you know, the, that one drug would fail and, you know, then we'd be like, okay, but there's this new biologic out, and we've maybe humera is going to be the thing or maybe enroll is going to be this thing. And it never was.

Kelly Owens 9:36

So then finally, in 2017, you know, I was on Stelara. And that was failing. And, you know, finally in February of 2017, my doctors said, you know, this is all we've got, there's there's no other drugs left to try. You're just going to have to be on high doses of prednisone from here on out. And I was just devastated. But then I remembered at that time this wonderful man, Dr. Kevin Tracy, who went discovered this new field of medicine called bioelectronic medicine.

Kelly Owens 10:09

And I had heard about it in 2014. And I reached out to him at the time, but they weren't yet in clinical trials. And so in 2017, when I hit my Crohn's wall, I remembered him and I said, Oh, I wonder if that Dr Tracy ever got to Crohn's.

Kelly Owens 10:25

And sure enough, they had just posted a clinical trial setpoint medical post of the trial, that I believe it was that same week. And so I bioelectronic medicine, for those who don't know, it's

the trifecta of three fields. It's neuroscience, Molecular Medicine and bioengineering. And the idea is that you can use devices to target neural pathways to have a certain molecular outcome. So with vagus nerve stimulation, what happens is when the vagus nerve is stimulated using electricity, it sends a signal down to the brain and it sends an electrical signal there. And then in the spleen, it releases a series of chemical reactions that release neurotransmitters and, you know, interact differently with T cells and macrophages.

Kelly Owens 11:20

And the end point is that then eventually, acetylcholine, the specific neurotransmitter, turns the overproduction of inflammation off in the spleen. So, um, you know, when we hit the wall in 2017, and I found out that there was this trial for vagus nerve stimulation happening in Amsterdam.

Kelly Owens 11:41

My husband came home and I said, Well, there is a trial, but, you know, we'd have to live in Amsterdam for six months. And he, you know, and I was kind of like downtrodden. Like, how are we going to swing that, you know, we can't even pay our bills now. And, and he was just like, Let's go, we'll figure it out. And so we sold everything that wasn't nailed to the floor, Sean sold his jeep, with my family and friends came together, and they raised \$16,000, for us to be able to go for six months, it was like, it was crazy.

Amber Tresca 12:14

Yeah, I can't even imagine that. And it's so great that Shawn was like he was all in and you guys were willing to try because it's a clinical trial. And, as I think most people know, like, clinical trials don't always turn out to be something that works, right. So, so pretty big swing, but at the same time, facing nothing but steroids to treat your disease. I mean, steroids are bad. So like, that's really wasn't an option for you either.

Kelly Owens 12:46

Exactly.

Amber Tresca 12:47

On the one hand, living in Amsterdam for six months, oh, boohoo.

Kelly Owens 12:54

Of course, we had to live in beautiful Europe for six months.

Amber Tresca 13:01

But you know, you weren't well at the time, and you know, so that may have made it a little bit less fun. And you are going to do a clinical trial, which can be, you know, depending on what they need from you a little invasive. So, you guys, you get yourselves to Amsterdam, you obviously had a great support network, which I'm so grateful that you had all of that, then you get in this clinical trial. And then, like, how does that all work? What was your daily life like there?

Kelly Owens 13:28

Yeah, so, you know, for the first two weeks that we were there, we weren't even sure that I was going to be accepted, because you have to meet certain clinical trial prerequisites. You know, so we, you know, we found out that I, you know, over the course of two weeks, I had a, you know, pre trial colonoscopy, and, you know, that kind of thing, and, and it's, you know, one of those, it's one of those things where, you know, it's the first colonoscopy that you have, where you're like, I hope my disease is bad enough that I can get, like, get accepted here.

Kelly Owens 14:11

You know, so, you know, for the first year, those first two weeks, were really rolling the dice. And, you know, so it was a big life move to go and not even know if it was going to not only know whether or not I was going to be accepted, but okay, is this gonna work?

Kelly Owens 14:28

I had a lot of faith that it would I had read a lot about the science of it. And it really made sense to me, it really seemed to me that, whereas biologics seem to negotiate with the body by electronic medicine really seem to command it. And so I was just like, I need something to, you know, steer my ship here. And it really seemed like bioelectronic medicine would do that.

Kelly Owens 14:49

You know, so while we were there, it was really tough to navigate being in Europe with active disease, you know, especially like, you know, Reverse there before my vergus nerve stimulator was turned on, you know, you're navigating, you know, hundreds of year old cobblestone walkways. And you feel all of those rivets in the, you know, cobblestones and, and, you know, sometimes when my disease was really bad for a lot of people with inflammatory arthritis, they can relate, you know, one day you could be getting around decently and then the next day you need a wheelchair, you know, so on the days that I needed a wheelchair, you know, that was definitely complicated.

Kelly Owens 15:31

I didn't take into consideration the fact when I booked our Airbnb, I didn't realize it was on the third floor of an apartment building without an elevator. So no, it was so weird. But you know, those are things that you know, when you have a disease, these are things that you all you factor into your life.

Kelly Owens 15:47

So okay, we have to be at the academic medical center at one o'clock, it's going to take us an hour and a half by train, you know, train bus and subway to get there. You know, but we also have to factor in how long is it going to take me to get down the stairs, how long is it going to take me to get to the bus stop, those were things that we factored in. And, you know, we're big believers and really just kind of trying to find the good in, in anything. So we'd be enduring all of this and trying to get me from place to place.

Kelly Owens 16:19

But we'd look around and just be like, Holy smokes, look where we are, you know, and, and I remember, you know, the sun, you know, we were there in the summer, and the sun doesn't set until well, after 10 o'clock. And, you know, we would just, we'd sit out on our balcony and just, you know, watch the sunset later than we'd ever seen a sunset. And, you know, and I think so many people with that when your livelihood is at stake when you when it's hard to wash a dish, and it's hard to get down the stairs, you appreciate simple pleasures so much.

Kelly Owens 16:50

In the midst of all of the chaos of trying to get around, we would just be looking around going like, Oh my God, who would have thought that those 2 17 year old kids would be in Amsterdam, getting you know, with me getting implanted with this revolutionary device that would zap me into remission. You know, like, it's just, you know, we kind of just kind of had to keep in those harder days, you know, where I would wake up in so much pain, which I woke up in pain every day, but um, the really rough days, just look around and go, wow, you know, like, how, how great is this life Crohn's...without Crohn's disease, I would have never lived in Amsterdam for six months, you know.

Kelly Owens 17:30

So it's like, it's, there's a lot of a lot of really wonderful things that came out of having Crohn's disease. And then that's not always an easy thing to say, because it's caused me and my loved ones a lot of pain. But it's also caused us to have these experiences that we would have never, ever had in our life, Shawn, and I would probably still be, you know, in Sussex County, New Jersey, you know, living among more cows than people and which isn't a bad thing. But it just, it wouldn't have with our life wouldn't have turned out though it didn't.

Amber Tresca 18:05

Yeah, and I think a lot of people with IBD and with other chronic conditions with would say the same, you know, sometimes you might have to like dig a little bit to look for the things that are that are good, but but I think you can usually, you can usually find them, I think you yourself are better at that than most people are just from knowing you the past few years.

[MUSIC: About IBD Emotional Piano]**Amber Tresca 18:37**

What do you think is different between the way you experienced sort of medical interventions in the United States versus in Amsterdam, and I recognize that you were part of a clinical trial, and that's a whole different world. But I'm interested in that. And then also, just like the nuts and bolts of what was that, like when they actually implanted this Vegas nerve stimulator? It's a surgery and how did that all go?

Kelly Owens 19:04

Yeah, absolutely. So let's see the United States versus Amsterdam and the Netherlands in terms of medical care. I mean, the doctors and nurses are fantastic. In both I've had, I've had

wonderful doctors and nurses in the US. And I loved my trial team at the academic medical center. I mean, they just were fantastic and loving and wonderful.

Kelly Owens 19:26

And I would say the difference is the differences are kind of funny, in that I, you know, here in the US were much more modest. I think in terms of like, you know, we're going to get Alright, Kelly, we need you to go get an X ray and you need to strip down but here's a gown. And in Amsterdam, they're just like, stripped down, and I'm like, Where's my gown? You know, so they're just like, what do you need a gown for? And I'm like remember going into one room. Where they told me to strip down and you know, the woman who the tech who sent me in did speak a whole lot of English. And so she sent me in and said, stripped down and, you know, meet me on the other side, and I'm just like, okay, and you know, of course, it was just gonna be me and her, but I go in the room and there's no gown waiting for me and I look around and I'm just like, just...down down?

Kelly Owens 20:22

It was very funny. And like, when I got my colonoscopy is the same thing. I'm like, Where's my gown? They're like, we're about to stick like a roto rooter up your butt. Like, you know, that, like, don't worry about it. And I'm just like, no, I need a gown. So, you know, it was it was very funny. They're Americans are much more modest. I've learned, I'm sorry for the TMI, but it was it was pretty, pretty funny.

Amber Tresca 20:45

No, it's very funny. I'm the same way I think I would have been bringing a robe with me every time I had to go.

Kelly Owens 20:50

You know, it was pretty funny. I was just like, by the end of it, I was just like, Okay, I get it. Like, we're just, we all know each other now. OK, here we go.

Kelly Owens 21:03

So that that was the main difference, I would say, you know, but I, you know, other than that, there weren't a whole lot of differences. So the actual process for implanting the stimulator was, you know, so I always tell people, my, my particular stimulator, you know, in our generation will understand this. Other generations might not.

Kelly Owens 21:23

My stimulator is like the Zack Morris phone. It's the, you know, was developed in, you know, like, probably 1999 and perfected over the years, you know, but I have a device that is, you know, the batteries in my chest, and there's a lever that goes up to my biggest nerve and a coil that wraps around it. Whereas the new stimulators, those are the iPhones, those are, you know, so they're, they're micro regulators, and they, they're smaller than like the size of a fish oil pill or a coffee bean. And they, you know, they just clamp around the vagus nerve. So you don't have to have the surgery in the chest like I did, you know, the process for it.

Kelly Owens 22:03

I think the surgery lasted about 45 minutes. I went home that night. And it was, you know, they put me under general anesthesia. And, you know, I had the device implanted and woke up feeling groggy. And, you know, the next day, I would say, the day after surgery is always the rough day, you know, that's when the anesthesia is worn off. And you're just like, your body just kind of feels like how, you know, so, but yeah, it took about probably two weeks to heal, and then two weeks, and they turned my device on. And the night that they turned my device on, I actually forgot to take my pain medicine. And so it was 11 o'clock at night, we're going to bed.

Kelly Owens 22:46

And I was just like, wow, I didn't and I realized I was like I didn't need pain medicine all day today. And so Shawn and I being you know, were skeptical, we were just like, Alright, well, you know, you're excited. You know, like, let's see where this goes. And then every day, I just continued to feel a little bit better every day. And about two weeks after the device was turned on. I was getting dressed and, you know, all of my joints, you know, prior to that point, were always swollen and encapsulated. So you know, you couldn't even really see the definitions of what those joints look like, you know, my knees look like little cantaloupes. You know, two weeks and I'm getting dressed. And I went to put my skirt on. And I realized that I could see my kneecaps.

Kelly Owens 23:30

And so we called that day, the great kneecap discovery of 2017 we were just like, I was like grab the camera. Um, you know, so and then I you know, every day just kept getting better. And, you know, I talked about before how, you know, we would have to factor in time to get to the bus and get to the train. And the day that we had our Holy smokes moment was, you know, we were running late for an appointment. And you know, when we lived at the time we lived in, in Hilversum, which is about 30 minutes south of Amsterdam. And so we would have to take, you know, the bus to the train, get off the train at another spot and get a different train and then get the metro and so in there on different levels, different platforms.

Kelly Owens 24:19

So that day, we got off the one train and we went to go get on another train. And I literally ran up the stairs to get to the next train. And they got to the top and I turned around and Shawn was nowhere to be found. And I'm like, Where does my husband We are late. And I and I looked at the bottom of the stairs and he's just got his mouth wide open looking up at me like you just ran upstairs. And we just looked at each other from you know, one set of stairs from the top to the bottom of the stairs and we're just like, wow, and it was crazy. And I would have these feelings where all of a sudden I would just get this urge like a little kid like I wanted to run.

Kelly Owens 24:58

And you know then about two months later, I think it was August 28, or August 30, maybe I was deemed in clinical remission. And then in October, I had my post trial colonoscopy, and in May, you know, four out of the five components of my colon were inflamed and had active disease. And by October, only two had inflammation and that inflammation had improved.

Kelly Owens 25:28

So, you know, so to completely healed and to get better, so it was pretty, it's pretty wild. I've never been in remission up until that point. So I had no idea what healthy would even feel like and it was, it was the craziest thing in the world to just go from feeling 90 to being like, I think I was 28 during the trial. And, you know, to go from feeling like a nine year old woman to feeling what 28 could feel like, was just this crazy. It was just this very strange experience.

Kelly Owens 26:02

And I always equate it to it's like when you when you move to a new town, and you're not really sure, where the post offices and you're not sure, where the best tires and you're not sure you know, what the backroads are to get from place to place. Kind of the same thing when you go from being really sick to really healthy is that all of a sudden, you just kind of don't know what to do with yourself. You're like, I I don't know this body, but I, I like it. So yeah, that's pretty amazing.

Amber Tresca 26:34

Yeah, no wonder you felt the urge to run every so often, you know, you were just feeling your new normal. had had changed. Yeah, I don't, I don't think we focus on that enough, with my own experience of being ill until having j pouch surgery. And then suddenly, like I don't, I didn't even know how to live, I didn't even know it was possible to not have to think about all of the things you were so worried about getting up and down stairs. You know, you were experiencing these 20 trips to the bathroom every day and trying to get through school with that.

Amber Tresca 27:08

And then it's like, well, when you don't even have that anymore, like, like, what do people do with their time if they're not in the bathroom?

Kelly Owens 27:17

Exactly.

Amber Tresca 27:17

It's really, really bizarre. So you're a success story here. And then, well, what happened next? So you came back to the States at some point, and then this is kind of actually changed your whole life? Right? I mean, not even just feeling better, but it has changed your career trajectory. So tell me more about that.

Kelly Owens 27:37

Yeah, absolutely. So when I came home, you know, I, I always joke with Dr. Tracy, you know, who's the founder of this field? You know, he founded it. And I, you know, I think he wrote the

inflammatory reflex paper back in 2002. You know, the vagus nerve being the inflammatory reflex. You know, he's a neurosurgeon who studies inflammation.

Kelly Owens 27:56

So he really understood that, you know, everything functions as a reflex, and our brain is a reflex organ. And, you know, so in the vagus nerve connects your brain to the body, and, and, you know, so I had been following his work for years. And, to me, he was just like, the coolest person, and still is the coolest person I've ever met. And, you know, I, I just, you know, when I came home, I thought, I have got to tell this guy that he changed my life, and he saved my life.

Kelly Owens 28:27

And so I emailed him, and in the subject line, I said, Thank you for saving my life. And he, he's so funny, when he does presentations, and he talks about this, he says that, you know, he'll, he'll show the, the email, and he's like, you'll see underneath there, like, budget, email, and this and that, and he's like, and then I see this headline there, the subject line, thank you for saving my life. And he was like, You have my attention.

Kelly Owens 28:54

You know, so he, he, he said to him, like, you know, I went through this trial, and I've been following your science for, you know, years now. And, you know, in this field and your work, and I said, you know, you change my life, and so he invited me out to the Feinstein Institute's where he's the CEO, to meet him and toward the labs, you know, to toward the at the time, it was the standard for bioelectronic medicine. Now, it's the Institute for bioelectronic medicine and, you know, meet the scientists who worked on this field, and continue to work on this field. And, you know, from there, over the course of the year that followed, I worked, you know, closely with his team, you know, my boss, John Cohen, and, you know, Meredith and you know, Emily, and we, you know, I participated in different events that they were organizing conferences and I gave presentations about my, you know, patient experience.

Kelly Owens 29:48

And about a year in, I said to my boss, John, now my boss, John, I said that, you know, I said on top of telling My story, there's more that I could do here, you know, and, and I said, I feel like I can really add to this field by telling the story of bioelectronic medicine and you know, that we can expand access to more patients and advanced research and, and he said, you know, basically, it's funny you say that because Kevin and I are, Dr. Tracy and I have been talking for a while now about you being a patient advocate.

Kelly Owens 30:24

And so, you know, we went into this, I started in January of 2019. And I, our goal, from the get go has been, you know, expand access to patients advanced this research, because there's so much more research to do in this field. And also, you know, government and public education outreach efforts to, you know, let the public know about this new field, let physicians know about it. And also, you know, let the government know, and our representatives about how this stands to change the trajectory, you know, of health care.

Kelly Owens 31:03

When we think about, you know, rheumatoid arthritis, for instance, in 2013, the US economy spent \$300 billion on rheumatoid arthritis. And that same year, patients with RA, lost 252 million in lost wages. And I'm living proof of what happens when you don't have that, that cost anymore. You know, like, we've estimated over the course of 15 years that my care probably has been around \$3 million. And, you know, now, I have a little magnet that I stimulate my Vegas nerve, and that's my, that's my medicine. And not only is that my, you know, given me my life back, but I'm no longer disabled of working, you know, so what does it look like when all of a sudden you take millions of people who are sick and disabled, and then all of a sudden, you give them their health, and you give them not only a treatment option that manages their disease, but they allow them to thrive in it, you know, so I'm really excited about how this will really transform how we look at disease, transformed patient care.

Kelly Owens 32:12

And you know, I always say, What if the next best discovery is trapped in the mind of someone who's currently too sick to think about it? And you know, what's our human potential, like when you give potential back to millions of people? You know, so I'm excited.

[MUSIC: About IBD Transition]

Amber Tresca 32:34

What would you tell patients, there's going to be a lot of patients that listen to this, who have not heard of the field of bioelectric medicine, and are listening to your story with great interest, what would you say to them.

Kelly Owens 32:49

I would say that one of the mantras that got me through so many years of active disease was, your current situation is not your final destination, from 2016 on, you know, Dr. Tracy did this TED talk in 2016, called how electricity could replace your medications.

Kelly Owens 33:08

And so when I was at my worst, I would be laying in bed with my legs propped up, you know, ice on my knees and heating pad on my back. And I would put my computer on my lap, and I would watch his TED talk on repeat. And I did that because it was my constant reminder that this guy's going to change my life. And he's going to change so many lives with this discovery.

Kelly Owens 33:33

And so I would say that hanging on to mantras and hanging on to hope, and remembering that this may be a crazy thing to say. But if there's, if there's ever a time in human history, to have the misfortune of having disease, now is the time, you know, because, you know, science has just made leaps and bounds and it will continue to, and the things that, you know, our parents or grandparents, what would have been a life sentence for them, is not going to be a life sentence for us, and hasn't been a life sentence for me.

Kelly Owens 34:09

And you know, one of the saddest things I see online that crushes me in the patient community is when I see patients say this is going to be the rest of my life. And I just, I can't emphasize enough how, how untrue that statement is because of advances and novel research like this, and how important it is that we that we do the work to make sure that we know what these advances and research are, that our doctors know what these advances in research are, and that we advocate for ourselves that, okay, current treatment options have have bridged the gap and we can be grateful for those. But we don't, we don't just say okay, the status quo is here.

Kelly Owens 34:58

So this is where we are it no more new discoveries that sit on discoveries. Like No, that's it. That's I mean, you know, Dr. Tracy's research, she's so, you know, he worked with, you know, the team that identified TNF and, you know, did the first studies on monoclonal anti TNF. And so, they so he, he discovered that inflammation is at the root of disease, and that, you know, that our immune systems are attacking themselves.

Kelly Owens 35:28

But then he continued on that, okay, now we know that now we have some drugs out so that people can have some relief, hopefully, if they can have some relief from these drugs. But that's not enough, we need more. So then, then he made the great discovery of using electricity to manipulate neural pathways and to treat disease.

Kelly Owens 35:47

And so I would just say, whatever it is that a patient is going through, you know, remember that there are the scientists out there that are doing these great things that are working to change lives and, you know, not just my story, but there's 100 other, you know, patients in the world between rheumatoid arthritis and lupus and krones, who have these stimulators, and, and are also doing really well. So, you know, so I think, I think that's the take home message is your current situation is not your final destination.

Amber Tresca 36:19

Kelly, thank you so much for coming on, and for talking with me and for being a light for me personally, and for lots of other people. You've given me a lot to think about just in our discussion, and then also my show notes are going to be lit because it's going to be so many things that I'm going to want to link to so that people better understand bioelectric medicine, and better understand what your life has been like being a vagus nerve girl. So thank you so much.

Kelly Owens 36:45

Thank you so much for having me. It was such a pleasure to be on and I can't wait to see you soon.

Amber Tresca 36:52

Hey super listener! Thanks to Kelly Owens for telling her story and for being a champion for patients. I'll let you in on how long it took us to make this episode happen. We had terrible technical problems the first time we tried to record and then a slew of scheduling snafus which was finally capped off by the pandemic. We ended up recording remotely and while it was a long journey to bring Kelly's story to About IBD, I know that it was worth it.

Kelly blogs about living with Crohn's, her experiences in the clinical trial, and her insightful musings on the human condition at Vagus Nerve Girl dot com. You can also follow her on Facebook, Twitter, and Instagram as at Vagus Nerve Girl. My favorite thing on her blog is her grit directory, and you're going to want to check that out when you are struggling. Follow her now because she has future projects up her sleeve and you'll want to be along for the ride.

Bioelectric medicine is an emerging field. Some of us who live with moderate or severe IBD will find ourselves looking for more treatment options. I'm putting links to resources so that you can learn more in the show notes and on my Episode 95 page on About IBD dot com.

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

About IBD is a production of Mal and Tal Enterprises.

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

Mix and sound design is by Mac Cooney. Theme music is from Cooney Studio.