

About IBD Podcast Episode 89 - Living With IBD and a Rare Disease - Aaron Blocker

Amber Tresca 0:05

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

Welcome to Episode 89.

Since 2008, Rare Disease Day is held on the last day of February each year. About 1 in 20 people will be diagnosed with a rare disease. Rare Disease Day is a global event to raise awareness for people living with rare disorders.

That brings me to my guest: Aaron Blocker. Aaron lives with Crohn's disease and an ultra-rare disease called hypophosphatasia or HPP. Not only did it take years for Aaron to receive the Crohn's diagnosis, but it took even longer to diagnose HPP. HPP is a genetic disorder, so Aaron was born with it and he has had symptoms for most of his life. People with HPP don't have enough of the enzyme that helps build bone. That leads to premature bone loss as well as a host of other issues, not to mention the fact that it's also quite painful.

Having both conditions makes treating the symptoms of each of them more complicated. Aaron describes how he went about getting the diagnosis of HPP and gives some guidance on what people can do if they think that they might have a rare disease.

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Amber Tresca 1:20

Aaron, thank you so much for coming on about IBD.

Aaron Blocker 1:23

Hey, good to be here.

Amber Tresca 1:25

Aaron, I was struck by something that I saw during this last Crohn's and Colitis Awareness Week you did the infographic that the Crohn's & Colitis Foundation puts out for folks to fill out tell a little bit more about their IBD. And I've known you for a few years, but I didn't know this about you that it took approximately 16 months, I think you said to get a diagnosis of Crohn's disease. Was that right?

Aaron Blocker 1:52

Yeah, you know, I first started showing symptoms and having issues when I was like 10, or 11. And I didn't get diagnosed until I was almost 18. So I was in and out the ER, they almost took my appendix out just to take it out. Because like, they just kept thinking that that was probably it,

even though there were some times that they saw inflammation on like a CT scan, nothing that ever would, I guess lead them to think that it was Crohn's.

Aaron Blocker 2:27

Went through all kinds of trying to get, you know, diagnosed, and I was I was almost 18 by the time we officially got it. And I was always like, very skinny, like malnourished. And I don't know if it was just something that they overlooked or weren't sure about or, you know, lack of knowledge. As far as like, you know, we live in, I live in a rural area. So I just think, a combination of things.

Aaron Blocker 2:52

And then, when I was at when I was diagnosed, it was determined that I only had deep small bowel Crohn's. So oftentimes, the CT scan or the MRI would miss it. It can't reach it with a scope. So that was one of the things so it just wasn't your, your typical, colon sometimes a little inflammation, but nothing that would ever indicate like IBD. Eventually got the pediatric IBD specialist who did a pill cam, it was like, there it is, you know, there's the problem. But it was very, very deep. I mean, like, the very middle of your small bowel, far behind everything. So yeah, it took a very long time. I was sick, I was malnourished. eventually got it took five years, six years.

Amber Tresca 3:39

Okay, Aaron, so I have like a lot of questions about this diagnosis journey. Okay, so you were so young, did you have a colonoscopy, you said they found some, they found some inflammation in your colon.

Aaron Blocker 3:53

I actually didn't have a colonoscopy for a long time. I think one of the reasons was that there was some inflammation, but it wasn't, like, significant enough for them to warrant a colonoscopy. And, you know, and somebody so young was one of the reasons they didn't really, it wasn't enough, I guess for them to just be like, let's go ahead and do it. And in the end, though, like to in the end, it wouldn't have really changed anything. I don't get scopes as we as often as a lot of people just because they don't do much. I've never been able to see I have one colonoscopy where my colon was inflamed. It wasn't also like ulcerated or anything like that, but it was inflamed. And they said it could have just been obviously IBD like creeping up but it's only been like once I think that a colonoscopy has showed anything. So I am usually a pill cam for my follow ups.

Amber Tresca 4:53

Another thing that I noticed about your infographic was that you listed constipation is one of your symptoms, which I don't really see see a lot and yet your inflammation was in your small bowel. So like, how did that all work out with Crohn's disease?

Aaron Blocker 5:08

Well, that was one of the other issues that did that kind of attributed to not being diagnosed for so long. So I dealt with constipation a lot like to the point of, you know, like obstructing. And there were times. I mean, there were obviously times where I did have like diarrhea, you know, your classic, you know, like, hey, this is probably IBD related, but most of the time is constipation. Their reasoning, I was told is, is where my disease is located, because it's it's deep, the inflammation, the scarring that I had, for some reason, just made it to where I was constipated more, you know.

Aaron Blocker 5:49

I think a lot of people seems they were saying, you know, people who have more like, colon or terminal ileum involvement typically have, obviously, your classic like, you know, diarrhea, for advice, but you can see, like all of that, because mine is so deep. It had a harder time, basically hard time getting through getting through to the colon and to get out. So yeah, they just attributed to location. But again, it it didn't fit your standard, you know, Crohn's disease, or IBD diagnosis criteria. And that was one thing that, like, led to the the prolonging of a diagnosis that they're like, oh, it's constipation, but it's probably not IBD. And then it actually was.

Amber Tresca 6:29

Yeah, I think a lot of people don't realize that constipation can be part of it, which obviously was a was a big contributing factor to it taking so long for you to get a diagnosis.

Amber Tresca 6:44

So you also live with another disease, as if the Crohn's disease wasn't enough, you also live with a rare disorder, which took even longer to get diagnosed. But you can tell me about that. And what you're living with is hypophosphatasia. Most people I think, in the community referred to it as HPP.

Aaron Blocker 7:08

Yeah.

Amber Tresca 7:09

This is a condition that you were born with. But why don't you tell me about this very long road to a diagnosis and a little bit more about what HPP is.

Aaron Blocker 7:20

It's classified as ultra rare, genetic, metabolic bone disease. So it affects the way that your body forms, strong bones, you know, the genetic mutation doesn't allow my bones to get calcium, magnesium phosphate, all of those minerals that you need for strong healthy bones are not able to go, to go into my bone. So it comes with, you know, skeletal, like osteoporosis and gives you or they call it like the soft bone disease. So like osteomalacia, where the bones are just very soft, though, that calcium, magnesium phosphorus that can't get into your bones collects elsewhere. So it builds up so for instance, like the calcium tends to build up in your kidneys, to where you can get kidney damage and kidney stones. And then it also can be like you can get calcium deposits like in your eyes or on your heart. And then the buildup of like the phosphorus

in the magnesium leads to issues with your muscles, like muscle weakness. A lot of people have nerve issues related to it also doesn't allow vitamin B6 to get out of your body.

Aaron Blocker 8:29

So your vitamin B6 is typically very, very elevated. Children, like pediatric version, they often have like vitamin B6 dependent seizures. It's classified as a bone disease, but it affects pretty much everything but I actually obviously I was born with it because genetic, but I was actually born with skeletal deformity. So I was born with bowed legs, both long bones is not necessarily super uncommon. So I did have to wear braces, but it never corrected. I started to break a lot of stuff, a lot of bones. I also remember I had a lot of bone pain. I would sit a certain way on the floor with my legs because they just hurt so bad.

Aaron Blocker 9:12

Probably around 10 or 11. I think like my first bone, I broke my fingers. I can't even tell you how many bones I broke. I broke a pretty much one of every, like major bone you can think of they just attributed it to being clumsy. You know, when I was 18 I was told that my hips were going bad. Developed with called avascular necrosis. They attributed that to prednisone use even though I was only on prednisone for a brief period of time.

Aaron Blocker 9:40

And then literally a few months later, they accidentally caught the AVN on a CT scan. Yeah, and they progressed really quick. They said they'd never seen it progress like that as fast as it was and somebody's also young so yeah, had his hips replaced when I was 20. Both of them the one thing that really kind of set everything off for me, personally it was when, when I dislocated my hip was 2016. I think when that happens, I was 20, About to be 24 and my right hip dislocated, but I wasn't doing anything like I was at home on the bed and I twisted and just shifted out. So ended up having hip replacement revisions.

Aaron Blocker 10:23

So they went in and just took everything out and put new replacements in. Because they came loose. The bone wasn't strong enough to keep the implants that I had in, so they had to make adjustments. And then right after that, I had a bone scan. And osteoporosis was so severe that they like they freaked out a little bit, just because it was so bad. Like, you know, they often compare you to like a certain age, like, like your bone is worse than an 80 year old like female who's like post, like all of their stuff. They like menopause and all that where they typically start blue. She's like, it's way worse than that. I was like, well, that's not good. I and they wanted to start me on the medicine for it. And I just wasn't necessarily comfortable with it...

Amber Tresca 11:12

...like an osteoporosis medication.

Aaron Blocker 11:13

Yeah. Like a bisphosphonate.

Amber Tresca 11:15

Yeah. Okay.

Aaron Blocker 11:17

And the reason I wasn't comfortable with is because one after I dislocated my hips, I started doing some digging in some of my own during my medical history, when I dislocated, I was like, This just isn't right. I've not been on steroids for a long time. Like, we just don't do steroids anymore for me. And just because of, even before HPP. You know, we just knew that, because of the AVN and everything that like steroids are just not an option. I mean, unless it's like last resort, you know, but I'm able to be in my Crohn's disease is able to manage without steroids now.

Aaron Blocker 11:48

So it shifted out and I was frustrated. It was something that was one of those moments in my life, especially with my wife that I kind of refer back to that was one of the breaking points. And I was like, This isn't right. And there was one thing that always bothered me about my medical history, even before and it was that when you looked at my bloodwork, my metabolic panel, and they do like pretty much everybody has done at least once. That alkaline phosphatase level was always extremely low. But I'm talking like, severely low. So like, the the normal level is adjusted for your age and gender and all that. But for me, like 40 to like 150, I think is normal. And I was like 10. So it was like significant.

Aaron Blocker 12:33

So yeah, I actually did some digging. Eventually, I thought that maybe it was hypophosphatasia. I came across a medical research papers, came across a couple things. And I was like, I think this, you know, this may be it. And the thing about that is, is that you for someone who has HPP you're not supposed to take the osteoporosis medications, especially the bisphosphonates. So I told my PCP who was great. He was like, you know, could be here we can get you tested took about a year. But eventually I had genetic testing to confirm.

Amber Tresca 13:06

After a lot of broken bones and other things. And then what about your vitamin B6, because that's also a factor.

Aaron Blocker 13:16

Yeah, so I never experienced any seizures related to that. I do have like the juvenile childhood can like version of the disease. But my level when we had my vitamin B6 tested, it was never actually tested until they suspected or till we went down the path of trying to get a diagnosis. It was like four times the normal and it was like four times higher than it should be, which is another telltale sign I do obviously in it. They say that it's not a whole lot known about the function of vitamin B6, apparently. But they they say that that also can contribute to someone might nerve issues. And most of the issues along with the magnesium and the phosphorus build up. I do often get really bad headaches. And they believe that is vitamin B6 related. So yeah, it was super high.

Amber Tresca 14:08

I want you to tell me a little bit also about your educational background and what it looked like for you to start digging to start looking for the reason for all of these problems that you were having. And when you suspected it was a rare disease. And so where did you start looking to understand what was going on with you and because essentially, you diagnosed yourself really.

Aaron Blocker 14:30

Yeah.

Amber Tresca 14:30

How did you get there?

Aaron Blocker 14:32

For educational background, I have a bachelor's degree in Biomedical Sciences and I have a master's in biomedical research. I've my educational background definitely helped. You know, there are certain things that I knew and could kind of pinpoint and I know how to read a research paper and stuff like that.

Aaron Blocker 14:51

So but honestly, like most patients, I just started, you know, online by googling and looking and so the one thing Even before I was had considered even a couple years before I kind of considered, I had always wondered about the alkaline phosphatase. Because I would get, like medical records all the time, like I would see my results, like I get that comprehensive metabolic panel, like, every time I go see my GI, that it always stood out to me.

Aaron Blocker 15:19

So when I started looking and googling, and, and all of that, I started with symptoms, but then I also ended up looking into alkaline phosphatase, and why it would be low. The one thing though, is that most places are like, if you come across a lot of like medical articles, oftentimes, they only talk about it being high, because there are more diseases and problems associated with high alkaline phosphatase instead of low. But you know, you have your one or two pieces that came up. And then at that point, once I kind of, you know, did some digging, then I looked in, like social media, you know, I've been working with a nonprofit, the Soft Bones Foundation, and they've been great. And, you know, we're working together.

Aaron Blocker 16:08

And I think that one, the low end did help, the sleuthing and I did a lot of the grunt work myself, I mean, I got a lot of my medical records and, you know, called around and, and really tried to dig in to just see, and, and the one thing that always came up and was always, you know, low was the ALP, on all of my records, is one of those things where I think that also having already have been diagnosed with a chronic condition for a long time, you know, I would think I was, what, eight years into my Crohn's diagnosis or so by the time, you know, this came through, and I already already understood what it took to be very involved in your care.

Aaron Blocker 16:51

It was not easy, but so a lot of it, I did all of it myself. And I did and ended up coming up with a diagnosis. That was correct. It took it I think from from the time that I started looking into it. So I started work in 2016. And it was almost 2018. Before we officially you know, got it. And I had to, I saw a few doctors locally and then a geneticist and then eventually got it. But yeah, it was a lot of just initial, what most people do. And they're either like newly diagnosed, which, again, we always say be careful with the internet. But we're gonna do it anyway.

Amber Tresca 17:40

So I know that you're on treatment, because I lovingly follow you on social media, of course. And I know just from the little bit of work I've done in the rare disease space, that treatments for rare disease aren't always really treatments. Sometimes they're just to manage symptoms. Yeah. So tell me though, about the treatment that you're on which, goodness, it's a...it's a it's a lot. So I'd love for you to tell me a little bit more about what that's like.

Aaron Blocker 18:11

So for HPP, there is only one drug available period that is approved to treat the disease. One thing is just need to know that like alkaline phosphatase is an enzyme that's important for bone health. That's, that's the enzyme that allows those minerals into your bone and you to be able to get rid of vitamin B6 and all that stuff. But it's just an enzyme in patients with HPP is a genetic mutation doesn't allow our body to make enough of that enzyme. And what we make is typically not that functional. So the one treatment available is called asfotase alfa, Strensiq, is an enzyme replacement. I mean, it's sure you know, there are enzyme replacements out there, but it's an enzyme replacement. So it's an injection is its weight based. So I do nine injections a week.

Aaron Blocker 19:05

But it does mean it definitely treats the disease itself. It's not a like silver bullet kind of thing. It's especially if then people like me where it took so long to get diagnosed. My body had already been, you know, ravaged with, you know, issues with bones and stuff like that. But it definitely helps it even in you know, there are some forms that are lethal to babies, but it has helped with that. But yeah, so it's just the enzyme replacement it you know, it starts allowing those minerals into your bone and, you know, allowing you to get rid of that extra, you know, calcium, magnesium phosphorus basics kind of lowered, trying to try to level all that out. But it again, it's definitely even even if you get diagnosed early and started they're still there. Somebody said it just can't do. You know, there are certain things that it's just not going to help with the disease's progressive, it can help slow it down, but it's not, not 100%. And it's a lot of injections. Do not a week right now, I was doing six a week for a while, um, it it does fluctuate based on weight. It's crazy. It's the only treatment. It wasn't approved, I think until like 2015. So yeah, it's, it's a lot, but it's definitely helping.

Amber Tresca 20:28

Well, that's good to hear. Because I would hope that it's helped.

Aaron Blocker 20:34

Yeah.

Amber Tresca 20:34

For crying out loud, plus whatever you're receiving for your Crohn's disease. So how do these treatments interact? Do they? How do the two diseases interact, we also know that IBD can affect your bone health, your bone health is are far and away...

Aaron Blocker 20:54

Messed up...

Amber Tresca 20:58

So they wanted to put you on something that could improve your bone health, but that's not gonna work for you, right?

Aaron Blocker 21:02

Yeah, right. In general, the treatments, you know, I'm on Humira for Crohn's and then Strensiq, for the HPP. They don't really interact with one another, per se. I mean, like, they're obviously fine to, like do and then. But one of the couple of the issues as far as not necessarily medication related, well, sort of, but some of the issues that, like you said, like Crohn's disease, like IBD has its own set of like inflammatory arthritis, and bone issues, especially if you've been on steroids, or mounters. And all of that can affect your bone health. So there are some times when I have like arthritis and, you know, issues, pain in my joints that we don't 100% know, whether it's Crohn's or HPP. So it kind of makes it hard to manage that sometimes, usually, so if it's like inflammatory arthritis, my inflammation levels are up, they typically attribute that to the Crohn's. But if that's normal, the nature of it HPP.

Aaron Blocker 22:09

The one thing too is that for like pain management, so HPP is really painful. You know, the skeletal pain is pretty severe. But often they try to manage that with stuff. I mean, like opioids if you need it, but a lot of it is they try to do like non steroidal, anti inflammatory, you know, the NSAIDs that we're not supposed to have with Crohn's, some pretty powerful ones out there that you can get prescribed that would really help with that pain. But I can't take those especially not long term, I can do like, you know, I deal with constipation with IBD. So taking pain medicine also attributes to that, obviously, there are times where I have to have certain I mean, sometimes I do take an NSAID, sometimes I do take pain medicine, and there's but there is definitely this overlap.

Aaron Blocker 23:00

And it makes it really hard from a mostly for pain management, it makes it really hard for my pain management physician to kind of navigate all of that just because of the interaction of what will disrupt due to the Crohn's disease or, you know, or vice versa. So they don't, it's not necessarily that the drugs themselves interact, it's just that there's definitely some, some

overlap of arthritis. But because of the problems like cancer medications, it's just like a balancing act of trying to figure out what to do.

Aaron Blocker 23:33

And then also, I mean, trying to figure out what, you know it what side effect or what symptom or what can you live with? Like what, you know, is it worth doing a short course of, you know, a powerful NSAID, you know, is it worth being on, you know, some pain medicine for a while that could potentially make your Crohn's disease act up, or getting more constipated. So there's just a back and forth and just trying to figure out, you know, the best way to go about it, and it's always a trade off, there's always something but this definitely makes certain aspects of treating each disease difficult. They don't always know if it's arthritis from from Crohn's, which what, which sometimes indicates active disease, whereas it could just be the HPP. And then, you know, they don't know it's just, it's frustrating. Sometimes we push through.

Amber Tresca 24:27

Yes, and you know, you don't really have any choice.

Unknown Speaker 24:30

You literally you don't gotta do it.

Amber Tresca 24:34

You got to do it. So you go to a special center to have your HPP managed, you know, your disease is ultra rare. So how many times have your physicians seen it? And are you a case report yet? Do you think?

Aaron Blocker 24:48

I am actually Um, so yeah, it's it's super rare. There are only a handful of physicians and In the US, that USA, the United States where we live, that are familiar enough with the disease, to treat it, and that are comfortable trying to manage it.

Aaron Blocker 25:12

But so here when I was diagnosed, what will the geneticists deny that, you know, did ran the test, but when I was referred to, like endocrinologist here, and then geneticist, they both were just like, we've never seen the disease before. Like, we've heard of it. We've never had a confirmed case. But he was like, I can get the genetic test on. I mean, that's, you know, that's like the easy part. So yeah, so once they did that, and I got diagnosed, they were, the geneticists wanted to refer me out anyways. But it took a little bit, so they never seen and they were honest with me, and they're like, Look, we were going to try to refer you out. Because we don't feel comfortable treating you here.

Aaron Blocker 25:54

One of the reasons was to get approved for, you know, the treatment, it's very involved, you know, you need because I was older. So the treatment is approved for like certain forms. And so pediatric childhood juvenile, if you end up having like an adult version of that, the

treatments technically not approved. But because I was diagnosed, when I was older, we had to prove that I had all this other stuff prior to 18. And they were just like, we can try, but we don't really, you know, we don't know, they did ask if they could do a case study on me. And I was like, Yeah, go ahead. So they wrote one up.

Aaron Blocker 26:29

But like, I mean, a couple good things was like, then there was a couple of, you know, people that came in from one of the foundations that talked to the hospital, and, you know, they had drug reps and, and the pharmacist came to the hospital to give lectures and stuff like that, you know, like on the disease. And so there is a little bit of a practice out of that was that, you know, more people now at the hospital with know, now I was a case study.

Aaron Blocker 26:54

But yeah, so I ended up going to I go to Vanderbilt. So it's the closest place to me with a physician is familiar with treating it, I love my physician, she's great. It's kind of like, if you see a regular doctor, and then it goes to an IBD doctor, and I'm like, Man, this is like, it's just the whole different. Like, they're just at a different level, you know, there's like this different, like, they're like, yeah, they get it.

Aaron Blocker 27:21

And that's kind of that's how it was, you know, I saw her and she does a lot of research on with the disease. Um, so it's an endocrinologist, like bone metabolism, is what she kind of specializes in. But she's been at the forefront of a lot of the research some of the drug trials, there are like, I think they're like 1300 or 1500 cases in the US that they know of, like, diagnose total, she's saying like, over 100 of those like cases, you know, obviously, she was able to get me on treatment piece my records together to kind of, you know, paint the picture that was needed, just to make sure that qualified for and I am enrolled in certain studies, there. So every time I go up, I have to go every three to six months. I've been in like several studies that that they have done.

Aaron Blocker 28:10

A lot of it is like historical and then, you know, they get x rays head to toe when you first see see them so they can see everything. And then I have like repeat, you know, stuff. So it was a lot but like in in the end and in the long the long run. It's been really amazing. You know, she She's incredible. It's been pretty great. It's very different from how I've had to deal with Crohn's. You know, there are definitely some overlapping. And again, chronic illness sucks, you know, it doesn't matter if it's Crohn's or HPP, it's just just, it's always a struggle.

Aaron Blocker 28:45

But there's definitely this divide between having something that's ultra rare versus something that a lot of people know about. And the fact that we have multiple treatments for for Crohn's disease versus one treatment for the other. And one treatment for the other that not everybody technically can get on. It's actually it's not FDA approved for people who are adults. Like if you have true adult HPP it definitely takes a lot of time. I mean, it takes two or three days

out of my week to go up, you know, to either fly or drive or, you know, I'm cramming in like, 4 appointments and two days and also testing and, you know, I have yearly like, x rays and stuff like so. It's it's a lot it's very, very involved.

Aaron Blocker 29:34

Just with like anything with Crohn's, you know, we we learn new stuff every day, it seems like you know, and we're treating it even with even when I was you were diagnosed with way before me with UC, but even when I was diagnosed in 2009, there was only like, what like three or four like biologics, you know, at that point, and then now there's a ton for IBD so it's just you They're learning stuff every day with HPP. And but they really need like, if you can to give them whatever information you can, you know, they want to study it, and they want to be involved and stuff like that.

Aaron Blocker 30:10

So it's, it's very interesting, it's a lot, but it's really cool. I've been involved in some really cool stuff, I did a research study where they kind of hooked me up to like a CGI thing. And I went into this room and like, like, the floor had like metal plates on it or pressure sensitive. And so basically, they just did, like, I would just walk around and this black CGI suit, they wanted to, you know, like CGI, and look at how my gait was, you know, my walking gait, how my skeleton was, and stuff like that. So I mean, it's been really cool. It also gives me an opportunity to contribute to research and to contribute to some, you know, some form of, of, you know, trying to understand you know more about the disease, and what can we learn and stuff. So it's been really cool. But there's a few downsides.

Amber Tresca 31:07

I think, if you have a rare disease, and yours is ultra rare. Is that an official designation? By the way, though?

Aaron Blocker 31:14

It is.

Amber Tresca 31:15

Okay. I think if you live with a rare disease, or an ultra rare disease, it's almost a given that you are participating in research. And like you said, you're in multiple research studies, whether they're observational or clinical trials, or what have you. But as far as you diagnosed yourself, you know, your your background probably helps you with that. Do you have any advice for someone who suspects that they or their child or another family member might be living with a rare disease? And they're trying to figure out where to go and how to get diagnosed?

Aaron Blocker 31:55

Yeah, I mean, I think that if there's any, again, any suspicion that you could have some sort of one some sort of disease, but some sort of rare disease, for sure. It's definitely harder to get diagnosed, and it has these just because you'll often can't find a physician that is familiar

enough with it. So for, for me, some of the resources that I used was, you know, the National Organization for Rare Diseases has a great, you know, they got all kinds of information.

Aaron Blocker 32:23

I would say this too, if you think you know, the rare disease that you may have, we have some suspicion of that, look for the foundations look for, you know, like a nonprofit, or, for me, it was Soft Bones, you know, obviously, they're nonprofits for IBD. But the rare disease foundations, they, they're familiar with, how hard it is to get diagnosed. So they often provide a lot of detail. And a lot of, you know, they have, obviously, they have certain physicians that they know, and they just have context that we'll be able to help you kind of navigate that.

Aaron Blocker 32:58

So I think that's one big thing that really helped me in a suspicion of that, I mean, is valid and should be sought out. So don't be afraid to ask your primary care. I mean, I took a research paper to my primary care doctor, and I was like, Look, this is what I found. This is kind of where I'm at. And he was like, Okay, let's do it, you know that. So don't feel like you can't bring that stuff to your doctor. But if you can't, if you bring it and they write you off, then then maybe go somewhere else. You know, I had multiple second opinions and then ended up at Vanderbilt.

Aaron Blocker 33:28

And, you know, I'm not a doctor, or anything like that, you know, and I don't know if, and obviously, my background helped but I honestly feel like it was also a little bit of luck. But you know, it's definitely intimidating like finding all that and then go into your doctor and being like, Hey, this is I think I have this be steadfast, you know, push for it, you know, even if, even if you're wrong, even if you end up not having what you think you have, you may have something else so I mean, it's but yeah, definitely look for, you know, look online. I mean, nowadays, there's there lots of communities, look for the foundations and just kind of don't be afraid to take point in your care and do what's best for you.

Aaron Blocker 34:09

I mean, and it's your health that your life your you know how you feel. Don't be and don't be intimidated to speak with your physician and be like, Hey, I think is this or can we check this? If they're not willing to pay then you need to go somewhere else.

Amber Tresca 34:24

Aaron, you're a dad and your son is super cute. No, I would be remiss if I didn't ask you a little bit about what he's into now. What's he doing? What's the favorite show, the favorite toy?

Aaron Blocker 34:38

He is into everything like everything yeah, he has so much energy it's insane. So what I it's a lot of fun, my kids to almost two and a half now. So his vocabulary is like developing at a rate that's fun, but also like he starts telling us "No" and stuff. Like, you know, it's great. I love your vocabulary, but I'm gonna need you to like, calm down.

Amber Tresca 35:11

Aaron, it has been such a joy to get to know you. And thank you so much for talking with me about living with Crohn's disease and living with HPP. And, you know, hey, happy rare disease.

Aaron Blocker 35:27

Thank you for having me. This has been fun.

Amber Tresca 35:36

Hey super listener!

Thanks this week goes to Aaron Blocker for sharing his story of his journey with Crohn's disease and HPP.

Aaron and I have worked together in the past and the last time I saw him was in January of 2020 for Crohn's and Colitis Congress in Austin, Texas. We were walking in an area with cobblestone sidewalks and I kept turning to him to ensure that he was OK with all the unevenness of where we were walking. At one point I asked him if his wife worried and if she felt like wrapping him in bubble wrap, because I was so worried about him getting injured and we were only walking to dinner. Rare disease has far-reaching effects and it's one of the many reasons it's important that Aaron tells his story and that more people hear it.

We touched on very little of Aaron's journey so I encourage you to follow him on Instagram, Facebook, and Twitter. I will put all his contact information and links to more about the topics we discussed in the show notes and on my Episode 89 page on AboutIBD.com..

Rare disease day is celebrated all over the world, and I encourage you to go to rarediseaseday.org to learn more and to participate.

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.

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Aaron Blocker 37:05

So I saw like a meme like a toddler meme or something. It was like the toddler was like saying their food was spicy as the parent was like "it's a pancake." [laughter]

Amber Tresca 37:15

[laughter] I have to find that because that is my kids.

