

Dr. Rochester: Hello, and welcome to Bold Conversations. A five part series on the immune deficiency foundation podcast aimed at advancing knowledge and understanding of Health Equity. Welcome to another episode of Bold conversations where we explore topics and issues related to HealthEquity. I am your host, Dr. Nicole Rochester, medical advisor for HealthEquity for the immune deficiency foundation.

And I am honored and thrilled and excited To have a very special guest today, miss Dionne Stalling. Dionne, thank you so much for coming on the bold conversations podcast today.

Dionne Stalling: Thank you so much for having me in the call. It's it's really an honor. So

Dr. Rochester: Dionne is a patient with primary immunodeficiency and several other rare diseases. Those of you that have been following the bold conversations series know that we've spoken to healthcare professionals and those related to healthcare policy, but this is such a treat to be able to speak to someone who is a patient and someone who has a lived experience. And I'm really looking forward to delving into this topic deeper with Dionne. So to get started, Dionne, I would love for you to share with the audience your die diagnosis journey. We know that the journey to diagnosis for patients with PI is long and narrowed. And the understanding or assumption is that if it takes eight to ten plus years for generally for people with PI. For those that are from minorities or marginalized communities, the journey is likely even more prolonged and difficult. So I'd love for you to share your own story about how and when you were diagnosed with primary immunodeficiency.

Dionne Stalling: Okay, Nicole. It's a long story. Too long for this podcast, but I will start the short version. It took forty five years. It took forty five years for me to get my first diagnosis. My first - what I thought was my first rare diagnosis. I didn't know that some other things that I had were rare, but I got diagnosed with primary immune deficiency in two thousand fourteen. Actually, on my mom's birthday was on a Wednesday. November twelfth of twenty fourteen was when I got diagnosed. The first memory that I have of my PI being a problem. I probably was about four four or five years old and I got bit by a mosquito. And that mosquito bite opened up like really large on my right thigh. And I got something called Empatigo. It was infected. It was really grotesque.

And now that I looked back on it, and I remember my mother was like, would you stop scratching it? The doctor said that if you don't if they told me that me scratching it was making it infected. And so we would go back and forth to the doctor with this same I still have the scar because they're open, probably about the size of a small orange. And antibiotics and the whole nine. I remember, I don't know if this doctor is still alive. I used to -- He used to be a regular at the emergency room here in Saint Louis at Saint Louis Children's Hospital, and he would always be the doctor that I would see in the and as you well know, this was in the early seventies -- nineteen seventy four. Seventy three, seventy four. And back then, there was not a lot of Black doctors that you could see. And also, we were coming off I can still remember my great grandmother saying that Black people couldn't visit regular doctors.

They had to see veterinarians. And so it was not common. I mean, it was not uncommon to go to the emergency room just like now to have a PCP. It wasn't lack of insurance. And I'm I'm sure that there was some kind of pay to pay as you go or whatever, but I used to see him a lot. And I would see him I saw him for that, and then he another doctor came in and said that she's scratching it too much, you know, all all all of that it and comes that you're making it dirty. But I

also used to go to the emergency room a lot for strep throat. I would have strep throat and ear infections.... I won't say monthly, but I remember it being commonplace for years, like even into adulthood. And only when I had his hysterectomy in two thousand eight, and that hysterectomy, I hemorrhaged.

And I'd bled for two days, almost two days. And when I went back and to get that hysterectomy repaired, that wound ended up getting infected. That was not uncommon either because I've had two children by c sections. I've had multiple myomectomies. Every time that I go under the knife, I always got infected.

And I was always told which is the craziest thing I was told, you're not keeping it clean. And I'm like, what are you talking about? Like, I'm wiping this with alcohol, so, you know, it's under the fold of the skin. I'm making sure it's clean, but I still was getting infected. And so to make a long story short, that infection led me to on a on a journey of trying to get well.

That infection turned in by me laying on the side that I was laying on for two days, I ended up getting a hernia. Mhmm. And I remember the doctor said that when I finally got in when they opened me up to fix the hemorrhage or to figure out where I was hemorrhaging and get all of whatever they do when they open you up. That I only had, I wanna say, two and a half quarts of blood. I had gone into shock, and they repaired it But from that point up until June of two thousand nine, I was probably in the hospital four out of the five months total.

It would be a I would stay in the hospital for a week or two, and then I would go home, and I would get worse, and I would go back to the hospital. I would say, stay a month. Then I would go back, I would stay two weeks. And it was when I left the hospital, I would always get worse because in the hospital, you're given antibiotics intravenously. You're not given them orally.

They would go send me home on oral antibiotics, but the oral antibodies, like I said, have never really worked on me. And I ended up going to my doctor wouldn't open me back up. And this is something that I would like to say we may get into it later. Doctors don't go surgeons will not go behind other surgeons. They will tell you to go back to the surgeon that you got the original surgery from, and my doctor had God Complex And he was like, and he delivered my daughter. And he had been my doctor for twenty plus years. Oh, you always get infected. It's not a big deal. It's just gonna take some time. Well, my home health care nurse was coming to my house in the wintertime.

It was really cold here in St. Louis, and I'll never forget it. It was really cold, and I heard the crackling of her some gravel coming up the driveway, and I opened the door And she was like, you need to call your doctor. I smelled you. And I was like, what?

And she was like, no. You don't not like a a a musty odor. She was like infection has a smell to it. And she said because it's cold outside as soon as you open the door to let me in, I smelled you. And I was like, okay.

So my doctor wouldn't open me back up and I have a friend that lives in and Maryland that told me exactly what to say because by this time I'm getting really frustrated. It has been months and she told me to tell him a lie. And she said, either he's going to open you back up or he's gonna refer you to another physician. That should help you. Well, he referred me to a gynecological oncologist.

And when I went into the office, he was like, little short man. He was like, I don't know why he sent you to me. I don't treat. I treat women with gynecological cancers. This is not I don't do anything at all with hysterectomies, and I didn't do this surgery.

He said, but he had ordered some tests. Before I got there. And he said, but what I do wanna let you know is that you have a bioduct that's blocked, and you have a hernia there, which explained

why I was having a hard time using the bathroom, but I was thinking it was stress, it was, you know, it was a it was a bowel syndrome or something like that. He was like, you need to get this fixed as soon as possible. And if you don't, you're gonna pass away.

And I was like, what? And I said, I just started a job because I had been off and work all this time. I started a brand new job. And I say, well, can't it wait six weeks? I need to get through the training because they sent someone here to train me.

And he was like, no, you need to get it done as soon as possible. And I was like, oh my god. Like, what am I gonna do? And it was across town, and I remember on the drive home saying, God help me because I have two kids. I had a young daughter and a a son that had in was in high school, or no, he had just graduated, but I'm like, I have children that I'm I'm trying to live for. And so I was like, okay, I had visited a lot of OB GYNs in the North County area of Saint Louis and nobody would touch me. So I I guess I was using my critical thinking skills, and I got on my insurance website. And I he because the doctor told me you need a general surgeon. He was like, you'd OBGYN doesn't really have to do this. Just get a general surgeon.

And so I was like, okay. Based on my experiences and what I've been going through, What's the richest zip code in Saint Louis? And I put that in the in Google, Even back then, it was an encyclopedia. And six three zero one seven is the the wealthiest zip code in Saint Louis, and there's only one hospital. In that ZIP code.

So it made it very easy. And I went on St. Luke's website and I click, you know, refer physicians, general surgeon. And I'm getting really excited I was like, okay, maybe this is gonna be the thing. So I called the office and I told the woman what I needed.

But I said, this is a result of surgery. And she said, well, the doctor that you are asking for, he doesn't do the type of surgery. So then I started crying, like hyperventilating crying because She was like, no, it's okay, but we have a this is a surgical group. We have a surgeon that does that. I say, we can't you ask him if he'll see me.

So I'm like, bawling and she was like, it's okay. So I was like, please make sure that he'll see me. So she said, hold on. And when they got me off of hold. It was him.

And I told him what happened. And he was, like, we need to get your records. I said, I have my records. I have my records and the pathology report from all of my hospitalizations. What happened in the operating room.

Because I couldn't read it. I didn't know why I hemorrhaged, I blamed myself. Because doctors have a tendency to blame patients. I thought that I didn't get take my I the thought I didn't get my off of my blood thinner quick enough. And he said, well, I'll do the surgery.

And so fast forward, the surgery he did what we thought was surgery. He opened me up and he said, I can't see. Your insides, you have if it appears like there is, like, some kind of bail or when I open you up, I would have to cut through infection and I close you back up. But I'm gonna refer you to a -- an infectious disease doctor. So fast forward because we're on a podcast, fast forward that infectious disease doctor was treating me for about five years, I guess, and he finally said, do you let's see if you have AIDS.

Have you had an AIDS test recently? And I was like, no. And he said, let's see if you have a HIV or AIDS, because that would underscore explain a whole lot. And I didn't have AIDS. And so he was like, I don't know what's wrong with you.

And now mind you, he had treated me for years. I had still had other surgeries that still are open today. This was back years ago. And he said, I'm gonna refer you to an immunologist. And she's one of the best in St.

Louis. And I'm okay, that's fine. And I trust this doctor with my life. I really do. And I was in her

office, a total a total of seven minutes talking, because by this time, you know, really micromanaging how doctors treat me, and it took her seven minutes of questions. Every question she asked me to answer was yes. Mhmm. You know, yes. And I was like, yes. And so she said, have you had a pneumonia or a flu shot yet this season? And I said, I've never had a pneumonia shot. And she said, you shouldn't because you're under 50 but I'm gonna give you a pneumonia and a flu shot, and I want you to come back tomorrow and we need to draw your blood. And so they did the vaccine challenge. And they sent it off to the lab. And on November eleventh of twenty fourteen, I was diagnosed with primary immune deficiency.

And when I tell you, Nicole, I I cried, like, my mother, my grandmother, my grandparents all died at the same time. I mean, like, cried to the point where I I had to go to bed because my head had expanded. Because it affirmed that there was nothing psychologically wrong with me because I had had doctors tell me, with other things, Oh, have you seen a therapist? You know, I've been I have I've had a sight consultant. I lost my vision when I had my daughter.

And when I went to the nurses' station to ask them to shine a little light in my eye. I don't know what that means, but I thought we need to do something. That I had a whole team of medical staff turn around and look at me. And when they looked at me, they were looking me like there was something wrong with me. And then that made me cry.

And I went to the room to call my doctor. And I said, there's something wrong with my right eye and I can't see. And he said, yeah, they told me that they thought you were having a bout of post postpartum psychosis. And so to get this diagnosis of something physical being wrong with me was a relief I didn't even care what it was. I just had a name for it.

Dr. Rochester: Your your... thank you. First thank you. For sharing that because I can imagine even though it's been some years that there is still some trauma associated with that. And so I just really wanna honor that and acknowledge that. I'm feeling it in my body and it wasn't even happening to me.

So thank you for sharing that so transparently and you know, one of the things that one of the questions I was gonna ask you, I feel like you've you've already answered it. So I'm just kinda kinda walk back through some of the things that you said because I really wanted to explore your specific experience as a Black woman with PI and and how, if any, how that impacted your journey. And and again, I feel like you shared that already. So I'm gonna highlight some things that you said. One is that you felt the need when you were searching for answers and searching for a surgeon that you had that internal wisdom that you needed to search Saint Louis, Missouri's richest zip code. So that tells me that you have had experiences that informed your, you know, your journey in the healthcare system and your understanding was that you needed to go where people that maybe don't look like you get care.

Is that an accurate statement?

Dionne Stalling:

Absolutely. Saint Louis is very segregated, and I've lived on opposite ends of the country, and I've never experienced racism medically like like I've seen here, not necessarily that I I experienced it. I've seen it happen to other people. I can also say that it's not just to be seen by Black doctors because I don't think that's the problem either. Yes.

We need Black doctors. We need Black everything. You know? To make make it look like the United States. The training that doctors get is not conducive to help Black people.

It's just not. It's because I had a Black woman tell me after being in the hospital for a week and they couldn't figure out what was wrong with me that I needed to see a psych a psychologist, and she was gonna write me a psych consult for an infection that would not go away. And it was making me irate that they were coming into my room all the time asking me the same questions. It's like I and Also, I've all of my doctors at one point were Black. All of them OBGYN primary primary care doctor, my gastroenterologists, all of them, because I've had these I've had I've been chronically ill most of my life.

I've just been able to manage it or, you know, not really think about it. And also, I am a type a personality person I get really not hyper focused, but I'm hyper vigilant about little things, and I do pay a lot of attention to detail, and it irks me to no end when doctors don't, when they brush you off and say, oh, that's not thing or it's like, do I need to be bleeding from the head and from my feet for you to pay attention to what I'm saying to you? And so as a Black woman being a caregiver. And also, I used to be the person that everybody likes to take to the doctor with them because I always ask very exact questions. What is that?

What does she need to do? Does she need to eat that with -- take that with food? Do we need to do this? Why is this not working? So that was that's been my role as a friend and a and a family member.

For as long as I can remember. And it's just it's really it was really it's frustrating even now to see that people who look like me don't get the same, don't get fair treatment. And then I'm also a woman. You know, textbooks in in medicine. I know.

I'm convinced they may have a Rebecca or a a Tina as an author. But they're written by white men. And it shows because it's very focused on, like, data. And it's, like, But if there if the people that are not in the conversation are not studied, then your data is flawed.

Dr. Rochester: Absolutely. Oh, you have touched on so many things. Okay? Yeah. You brought up so many really good things. I wanna I wanna unpack one of them, and that is to underscore what you said about the solution is not solely to have more Black doctors. And you also said, and I agree with you, diversity is important.

And we've had other conversations in this podcast series about the importance of diversifying the healthcare workforce. And as you stated, that is not the sole solution because at the end of the day, due to structural racism, which permeates medicine and healthcare, you still have individuals that are practicing within a system that was not designed to properly care for Black and brown and other marginalized communities. So I really appreciate you highlighting that And then the other thing that you talked about is just this idea of really gaslighting. You know, what we know is common in medicine, it's common particularly with women patients and then even more so often with Black women or Latino women or disabled women, you know, that's that concept of intersectionality where I'm a woman and I'm something else. So the idea of medical gaslighting is, you know, that you are going you're taking care of yourself the best way you know how you're being blamed for your own medical condition and you're being ignored and your concerns are being dismissed So, you know, you really have just highlighted, I'm sure, again, the journey of many people with PI, but but also underscoring the elements about being a person of Color that make that journey even more difficult.

So I really appreciate you sharing that. And it's so fascinating that do all of that when you finally got to the specialist, the immunologist, you know, who sees this all the time, seven minutes. Of of questions and answers, and and you had your diagnosis. And I also just wanna highlight what you said about the relief. You know, I mean, it's like no one technically would celebrate having a

diagnosis of primary immunodeficiency.

But for you, it was validation all that you had gone through, all that you had been telling doctors for years and years and years and finally having an explanation for the things that happened to you. And and no, it's not in your head. So I I again, I felt that. I I felt that in my bones. I just appreciate you you sharing that.

I would love for you to talk a little bit about your experience with connecting with other patients with PI who look like you. Have you had an opportunity to connect with patients with PI who, you know, are Black or have another, maybe they're a member of another minoritized group because again, we know this is a rare disease And then we also know that within PI, somewhat due to under diagnosis and misdiagnosis, we have not yet identified a lot of patients that look like you.

Dionne Stalling: Okay. So let me tell you. When I got myself together by that Sunday. This was on a Wednesday. I'm telling you I cried until I couldn't really see.

But when I got myself together, it was on a Sunday. And I googled primary immune deficiency. Because I this is the thing. I knew what primary immune deficiency was. Right?

Because this is gonna sound really strange and and I'm an empath. Right? I remember David Vetter they called him the boy and the bubble. And it always made me feel bad. Like, why did they call him that when he was on the news, I remember it was on ABC back in the eighties.

They did some kind of I I think it may have been on twenty twenty. I will never forget it. And I used I cried for him because I was like, how horrible is that to have people looking at you through a glass, like you're a specimen. Right? And he didn't have friends to play with.

He couldn't go outside. Like, all of the things. And so I knew I remembered that. I didn't know that there were so many immune deficiencies. Right?

I have sub class IgG and CVID common variable immune deficiency for those people who don't know what that is. So I knew that part, but I went to Google and I found the IDF. And I started volunteering for IDF. And I I volunteered for years and I still do in some capacity. There are education days that take place.

And I think I had attended two or three education days before I ever saw a Black person. And it was a a a young a young Black boy probably about ten and his parents came. Those were the only people that I had ever seen, and I was so excited to see them. But I I was volunteering at the event, and I didn't get a chance they left before I could get a chance to talk to them. Because, you know, education days run from, like, eight thirty ish to three.

It's an all day thing. And I didn't get a chance to talk to them, but though he is the only person that I've ever seen in person. That has it. But you know what happens, Nicole, when you carry this type of trauma, I'm just realizing this is trauma. This is because of my therapist.

That every time that I hear someone says that their children have chronic ear infections or they have to get tubes. I'm like, make sure you have them tested. You have no test for this, this, and this, and this, you make sure no. Ask for an immunologist. So and I don't like people to give me advice, but I feel compelled to have to do something because your baby is not getting ear infections just because ... just because. there is a reason.

And I find myself doing that a lot within a Black community because I know that we are so under diagnosed. I just I know it. And I I feel it babies that have colds all the time. That's not normal. They oh, they go to daycare.

No. It's something wrong with their immune system like stop. So I have to stop myself, but those are the only times that I ever remember seeing in person. But now with the IDF, you know, when

you all do the walks, I've seen, like, pictures and things like that. I've never been part of that. But I'd seen pictures, but I've only been in the company of in the room same room with one person one other time that I that I know of.

Dr. Rochester: Wow. I appreciate you sharing that. And I love you're leading me into my next question as you talk about this this help being compelled to share with other Black families or mothers or fathers of children, you know, make sure you do this, make sure they get tested for that. And you are a natural advocate. And so I really wanted to also ask you about your organization because you're not just an advocate with friends and family members or people that you may meet, you know, you have founded a nonprofit organization rare and Black, and I'd love for you to talk about that and just share briefly with the audience, what your organization does?

Dionne Stalling: Well, rare and Black was founded on I'm I'm a -- I'm big on birthdays and symbols and all of the things. Rare and Black is my baby, and it was founded on March twelfth of twenty twenty, which was my grandfather's birthday. And my grandfather used to my grandfather and my great grandmother with my infections or things would always give me, like, old wives tales, like, I every Sunday, I would have to drink cod liver oil, Black draw, Black draw, cod liver oil, all all of the things to get me to be able to be healthy because this has been a a lifelong thing. Right? And so rare and Black was I remember my godmother when I was going through this.

Before I got a diagnosis, she was like, You need to write a book because I I'm a I'm a writer too. You need to write a book. And she was big on the NAACP. She used to be involved on a national level with NAACP. So it was only right that -- and I've always been a person that likes to bug the system and and not and a nonconformist and I used to get put out of school because of my mouth and you know, me challenging decisions.

That's just my nature. I don't like people telling me what to do, and I don't like people to to tell other people what to do, like let people live. So, rare and Black's mission is to empower and uplift Black people living with rare diseases. And also to make sure that they have advocacy promotion and we drive legislative change because a lot of issues that rare patients have is based on policies and procedures, not just legislatively, but structurally and institutionally that affect their that affect their their treatment and how they're treated. And also education.

I'm huge on like, I used to when I was little, I used to be my the teacher and my friend we would play school, and I would be the teacher. And then when you pass the grade, you would set up another step. And so I'm a natural I'm curious by nature. And so I also believe that Black people as a whole, there you know, in this day and age, the Internet is huge. And there is a what I'm what I feel, this is my feeling.

Don't come for IDF. And don't come from me. There's more bad information that floats among the Internet through social media than it is good. Because you can get on there and say, hey, Nicole, did you know that humorin can cure herpes, and somebody can re tweet it, and re tweet it, and re tweet it, and re tweet it. You remember with COVID.

If you put your head over some water on the stove, that and it's like, no. So I believe that educating in a responsible and productive and effective manner would help Black people because I have nine rare conditions. And It's hard to explain to people how I am or how I'm feeling because I don't look sick. Right? Nobody ever I had to tell someone the other day.

If you see me out if you see me on Capitol Hill, If you see me speaking somewhere, please understand that it took a lot of mental -- it took a lot of mental dexterity to get me here. I also

have to debrief if you see me for a week somewhere, please understand it's gonna take me two or three weeks to get back. And if you see me back to back, like, this coming week, I'm going traveling for a week, and then I got a two week I mean, a two day thing and then I'm gone for a week again. Please understand that it's taken a lot for me to show up. And I'm only showing up because I think that it's beneficial.

And the education piece, I do this so I can take in information so I could pass it on. And what I'm finding, what has been the biggest struggle for me this year is loved ones, loved ones, like really close loved ones that I have had have passed away from rare cancers, and they did not want treatment. They wouldn't even go to see like, my aunt passed away in May, but she would not go and see an oncologist to tell her what the options were. She went with the diagnosis, and she was like, I'm not letting them put that in me. And I'm like, but chemo is so much different.

Like, can we just be educated? Just be educated. Right? Go and see what they have to say. And if at that point, you feel like, okay, I don't want I don't do wanna do radiation.

That's fine. But find out what your options are so you can make an informed decision. I don't want anyone to be ignorant. And people say that there that's a bad word. Ignorance is without knowledge.

Right? I don't want you to be ignorant to the fact that there are constantly things that are ever changing, especially in the cancer landscape. You don't necessarily have to, you know, be doubled over after you come get from getting your chemo treatment. And you don't know, in these rare cancers, I have one of my best friends now, is battling a rare cancer. And I really have to pray and talk to her and say, just give it a try.

Like, if you get two treatments and you feel like I don't wanna do this anymore, then don't. But I'm finding that that's with older people and Black people have a reason not to trust the system, but everybody in medicine is not bad. You know?

Dr. Rochester: Correct. And that's why your organization is so important because you've highlighted and we've had another episode about this as medical mistrust, which was earned, you know, it's not by accident, And so I can only imagine for you and being the face for rare and Black and having a place where people who may be mistrustful of the healthcare system for ballot reasons, have an opportunity to get information. And basically, you're a trusted voice. You know, you're you're a trusted individual.

And I and it's just it's so important to have that, especially in the rare disease space. And we're we're very thankful that despite all that you've gone through and all that you have described, you still have found time and space to advocate for others. So thank you for that. And as we wrap up, this has just been riveting. I have one final question And I know, you know, and you shared some tips and and I hope people go back and listen to this over and over again, healthcare providers and patients and families alike.

But I'm gonna ask you to boil it down to one nugget, one piece of advice for healthcare providers and one piece of advice for either patients or families with regard to advocacy, with regard to rare disease, you know what? Because you've learned a lot in your journey. So if if you could offer one piece of advice for the medical community, what would you say?

Dionne Stalling: I would tell anyone that is seeing patient front facing that to be more curious. Right? Don't necessarily go by the textbook. Right? Because when I go to the emergency room, when I had staph and MRSA, do you know what my temperature was?

My temperature was ninety seven point four. I had staph and MRSA at the very same time. No

no I don't get temperatures of a hot got a temperature in twenty nineteen, and the nurse thought that I was going crazy. I'm like, oh my god. She was like, She was like, hon, what's wrong? I was like, I haven't had a temperate over twenty five years. Like, you have no idea how happy this makes me So that lets me know my immunoglobulin therapy is working. Right? So I want anyone that sees patients to know that you don't know what a rare disease patient looks like. Like, you have no idea because I get told all the time, oh, you look at your skin is looking real what are you doing with your skin?

And it's like, do you know I have five open wounds? Like, five? And so I want them to understand that to be curious to find out what is going on and not to just jump to the textbook because we're not in textbooks. We're rare. Right?

And unless they are curious by nature and wants to study us, then there are no textbooks. So make sure that you are really thinking about the whole patient. And be trauma informed, meaning, ask me always having the question in the back of your mind, especially if you've seen this patient more than once. With the same issue, and they're acting a certain way. Right?

Because they write down notes. I've been written about patient is hyper vigilant, she's non compliant, all of those things. Right? But find out why why are you that way? What happens to you to make you do this?

Or why are you making this decision? If I don't wanna take this, why? That's my thing for a patient. I mean, for healthcare providers. And the second for patient is if you hear nothing else from me, please hear me well.

You can leave your doctor. I don't care if he births all of your ten babies and he and your uncle play golf at the golf club course if you have been knowing him. If he treats you for free because the OBGYN that I was telling you about, he had treated me when I didn't have any insurance, and I trusted him. If you are going to a doctor for pain and you've been going to him for a year and they can't figure out what's -- leave. You're not And I tell people this a lot when I'm talking. You are not married to your doctor. And even if you were, you can get a divorce. We live in a time. You can just I'm I'm changing. Like, I want I want something different.

I want patients to know that the doctor works for you, not the other way around. If you have a doctor that talks to you like you or an invalid and you have some type of issue that they can't get past, leave them there are many doctors. And if you can't find get with an organization, that can help you find a physician because I meet people all the time all over the country that see doctors here in Saint Louis that have never stepped foot in Saint Louis, but because They may be an endocrinologist that specializes in this rare condition. They're the only one in the country that has published papers they see them just do due diligence, and everybody doesn't have the same health literacy, but find somebody to help you.

Dr. Rochester: I I love your advice. Absolutely love your advice. Dionne, thank you so much. As we close, please let the audience know how can they find out more about you and rare and Black.

Dionne Stalling: You can find red and Black on all social platforms at red and Black. So we are on LinkedIn at rare and Black, Instagram at rare and Black, and you can go to our newly we're working on website, but it's rare and Black dot org.

Dr. Rochester: Awesome. Thank you so much to

Dionne Stalling: you for having me, Nicole. It was a pleasure.

Dr. Rochester: Same. Thank you.