

Real Health Podcast

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Episode #38: Cancer Journey inspires Believe Big with Ivelisse Page

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Intro: This is the Real Health Podcast brought to you by Riordan Clinic. Our mission is to bring you the latest information and top experts in functional and integrative medicine to help you make informed decisions on your path to real health.

Dr. Lucas Tims: All righty. Okay. Thanks everyone for joining us. Another episode of the Real Health Podcast, I'm your host, Dr. Lucas Tims. And I have the extreme pleasure of being joined by our guest today, Ivelisse Page, who is the executive director and co-founder of the Believe Big Organization and the Believe Big Institute of Health. Some of you may have heard of Believe Big, but if not, you're going to learn all about it today and how Ivelisse through her journey with a cancer diagnosis and overcoming that, how she was able to transform her hardships into a real positive light through her organization to help many more patients facing cancer. And some of the really exciting things that they're doing, not only with supporting patients, but with research. So, Ivelisse, thank you so much for joining us today.

Ivelisse Page: Thank you, Dr. Tims, for having me it's quite an honor.

Dr. Lucas Tims: Oh, my pleasure. We've been fortunate enough to cross paths a few times over the last few years and such a fan of you, what you do, everything that your organization does. We've had so many patients that have benefited from the grants of Believe Big in helping to support them with the therapies that they get through our facilities. And so, a big thank you on behalf of our clinic and our patients. One of the things that we wanted to do today with the Podcast was to really allow our listeners to hear your story. I think, hearing stories of other cancer patients who have overcome the odds and not only survived, but thrived as you have is very inspirational empowering. So, if you don't mind, take us a little bit through your journey from leading up to your diagnosis and everything that transpired thereafter.

Ivelisse Page: Yeah, sure. Well, I was a busy mom of four. I was actually homeschooling my kids and working in the evenings. So, when I got extremely tired, I felt I was just burning the candle at both ends. And once the summer hit and I was still extremely exhausted, my husband and I knew something was wrong. I had to take three hour naps a day and that began the investigation to figure out what was happening. And we went through a series of tests and the actual test to rule out cancer actually was the one that discovered the cancer. I hadn't wouldn't been suffering from just extreme fatigue. The interesting thing is that I knew the symptoms to look out for, and yet I didn't experience any of them. My father was diagnosed with this very same type of cancer at the very same age that I was diagnosed.

Dr. Lucas Tims: Oh my goodness.

Ivelisse Page: Yeah, he died two years later and I was 13 at the time and since I was 18. I was doing all the conventional -- watching and testing to make sure since I was high risk. I was doing everything right. So, when I was in that hospital bed and finished the colonoscopy to rule that out, the doctor comes in and here's what no one wants to hear, "You have cancer." So you can imagine the tears began to flow and fear tried to set in, and the thought of not seeing my four kids grow up and growing old with my husband, Jimmy, was really overwhelming.

Dr. Lucas Tims: I mean, all from just feeling fatigued and take us back a little bit. This was a while ago, you were very young. I mean, you're still very young, but back then, even younger for someone to be diagnosed with advanced stage cancer. How old were you?

Ivelisse Page: I was 37.

Dr. Lucas Tims: Wow.

Ivelisse Page: 37.

Dr. Lucas Tims: And even though you had this genetic risk or susceptibility that was known, it was still caught you off guard, obviously, being at that young of an age. And for the only symptom really being fatigue, right?

Ivelisse Page: It was the only symptom, and the fatigue led to blood tests that showed that I was severely anemic. So anemic that my doctor at his office -- he could do the blood test there -- he said, "You have to go to the emergency room right now. Your organs can fail at any moment." My levels were so low and that's what, you know, got me to the hospital and they started to run all these tests to try and rule it out. Well, try and figure out what's happening.

Dr. Lucas Tims: Yeah. For most people that aren't aware, anemia is something that can be caught on basic blood work, but a female, who's 37 likely they're not running these types of labs periodically until you get a little bit older. And so, without the fatigue symptom, you probably would've never had that blood work done. And the reason the anemia is caused is because when you have a tumor in your colon, it's leaking blood. And so, you're getting a lot of blood loss that way. And that's what leads to that anemia. But, the other part of it is that typically in this country, we're not doing colonoscopies on people until they're at least 45, usually 50. So, there would've been no other way they would've caught this.

Ivelisse Page: No other way. Mine was also in very high in the colon. And so, it wouldn't have been typically found. And so, that's why the typical symptoms I knew to look out for because of my dad's case. I was getting a colonoscopy every five years, I was looking out for those symptoms and outside of fatigue and that could be so many things as a busy mom.

Dr. Lucas Tims: Sure. Yeah, you could write that off to stress or not sleeping well, or just too much going on for a long time. And it sounds like you did for a little while until it just got too severe.

Ivelisse Page: Yes.

Dr. Lucas Tims: So, you have the colonoscopy, they identify the tumor, but it wasn't just in the colon, correct?

Ivelisse Page: Well, it was in the colon originally and they went ahead a week later, I had my colon resected. And at that point I thought we were done because the pathology came back that I only had one lymph node out of 28 affected. And it was only because my surgeon said, "Do your due diligence. I know you're declining the chemo and radiation, but do your due diligence and go see an oncologist." So that's when I went to three different hospitals and I spoke to three different oncologists and it was the one at Hopkins who performed a CAT scan on me instead of a PET scan. And when I asked him, "Why are you doing a CAT scan?" He goes, "Well, Ivelisse, your tumor is mucosinase and it will hide in a PET scan. So we really need to make sure that this imaging can see everything we need to," And it was in his office when we were discussing all the options that the report came back. And it said that I had three lesions on my liver. And so, it was at that point that I was stage four.

Dr. Lucas Tims: Yeah. And just further context for the listeners, typically when they remove a tumor in the digestive tract, they will sample lymph nodes in and around that part of the digestive tract. And so, they can sometimes take up to 20, 30 different lymph nodes. And as you said earlier, only one of those had cancer in it. Now, cancer can spread through the lymph nodes, but it can also spread through the bloodstream. And the bloodstream is how it can get to other organs. And a very common place it can spread is, especially with colorectal cancer, is to the liver. So, anytime it's gotten past the lymph nodes into another organ, you're automatically classified as stage four. Which another thing that comes along with that is ... oh, by the way, the chance of you surviving this and being cured goes down quite low.

Ivelisse Page: Yes. They told me that my chances are survival 8%.

Dr. Lucas Tims: 8%.

Ivelisse Page: 8% survival.

Dr. Lucas Tims: You're 37 years old, been healthy all your life, done all the right things, and here you are being told that you've got an 8% survival chance.

Ivelisse Page: Yes.

Dr. Lucas Tims: Yeah. I can only imagine how that rocks your world.

Ivelisse Page: Oh my goodness. It was the biggest challenge. I even tell people that the fear and anxiety that tries to set in, I think, was more difficult than dealing with the surgeries and the cancer itself. I always feel there's a saying that people say that says, "God won't give you anything you can't handle." But I actually believe he often allows situations that are too much for us to handle alone. And, I think, it's in these times that we realize how much we need each other. And most importantly, our need for him becomes so obvious.

Dr. Lucas Tims: Wow. That's so well said. I love that. Yeah. Because like you said earlier at this point you've got four young kids, right?

Ivelisse Page: Yes. My youngest was five and my oldest at that time was 13.

Dr. Lucas Tims: He, he already had tough tasks for you.

Ivelisse Page: Yes.

Dr. Lucas Tims: Four kids. So, he was really sending you a strong signal that you had a big fight ahead of you and that you needed to amass your troops, right?

Ivelisse Page: Definitely.

Dr. Lucas Tims: So how did everything play out from there? Obviously you get this stage four diagnosis, your Earth's been shot, rattled a little bit. Talk us a little bit through everything transpired after that.

Ivelisse Page: Yeah. So, I was sitting in the appointment with him and I actually had a whole list of questions that now we share with patients to ask their oncologist, and one of them was ... and this was before the report came in that I was stage four. I asked him, I said, "What are my chances of survival? One lymph node at a 28 affected I'm 37, I'm young. I'm healthy. I don't fall into the regular bucket of a 65 year old plus having colon cancer." And he looked at everything and he said, "At that point, you have a 67% chance of survival." I'm like, "Okay, that's great. Okay. Not too bad." And then this was the question, Dr. Tims, that just floored me. And I asked him, "What are my chances of survival if I did nothing?" And he said, "57%." And I looked at him and I was like, "Wait, you mean, if I did nothing, there's a 10% difference?"

Dr. Lucas Tims: Right.

Ivelisse Page: And so, that is a question that I feel isn't asked a lot and I feel like really helps you to make wise decisions. And so for me, then the report came in and said I was stage four. And he said, "Well, you can throw all that out the window. I will work with you with your more natural approach that you'd like to do, but let's get you scheduled for surgery for your liver." And during that time, two people from two different walks of life told me that I had to speak to Dr. Hinderberger, who is one of the mistletoe experts here in the US. And I took it as a sign that I had to go see him, and it was at his office that I was told about mistletoe. And I was like, "As you know, isn't that what we see it Christmas time?"

Dr. Lucas Tims: Yeah. Right.

Ivelisse Page: I didn't realize how this amazing plant had so many incredible chemotherapeutic substances in it to help my body fight for itself. And it was there at his office that I had my first injection of mistletoe. And back then there wasn't an IVC, IV mistletoe that was available, at least in Maryland, where I was being treated. And two weeks later, I went in for surgery for my liver and 10 weeks later I went for my follow up and it was ... I put December 4th, 2008, as the day when there's never been visible cancer in my body again.

Dr. Lucas Tims: Wow. It must have been as tough as the diagnosis prognosis conversation you had after your initial surgery was when they found the liver lesions, it must have been equally as sweet on the other side of things when you got that information.

Ivelisse Page: Yes. Yeah, it was.

Dr. Lucas Tims: As we know, there's no guarantees even when they go in for what's considered a black and white surgery or, "Hey, this is going to be easy." You just never know.

Ivelisse Page: Yeah. And he actually told me when we went in for our follow up, it was the 10 weeks. I said, "What are the chances that it comes back that you'll see something on this scan?" And this was 10 weeks later. He says, "You really want to know?" And I'm like, "Yeah of course I want to know we're dealing with here." And he said, "75% of the time, the cancer's back." And I remember my husband looking over at me and he was like, "You're going to be part of the 25." Thankfully, I was.

Dr. Lucas Tims: Yeah. Because what most people don't understand is that what you see on a scan and even what the surgeon see when they get in there to cut it out, there's always more than what meets the eye when it comes to cancer. And unless you can get down to the cellular level, you really never know the full scope. And, I think, if you ask most cancer doctors, they tend to overestimate the likelihood of cancer coming back. And, I think, one of the reasons why is that they know that the body's ability to defend itself has been severely compromised, right? And they know that their treatments, whether they admit it or not, make that a bigger issue along the way as well, chemotherapy, radiation, what they don't tend to account for is someone like you who has stepped outside the box, if you will. And maybe just by divine intervention, started working with Dr. Hinderberger there and actually was doing something that increased and reengaged your body's ability to defend itself through the immune system. And that was with the missile toe therapy, correct?

Ivelisse Page: Yes.

Dr. Lucas Tims: And through that, how big of a piece of your puzzle it was could be argued or debated, but when you think about the odds and you think about how you chose a different path, to me, it speaks quite strongly about the power in some individuals cases of a therapy like mistletoe. And I know that you've made that a real calling card for you and everything that you've done with your organization, and it's probably good for the listeners to put a bow on and say, 'You're still cancer free, right?' 13, what is it? 13 years later?

Ivelisse Page: 13 Years. Yes.

Dr. Lucas Tims: And, but take us through the transition from getting to that state of no evidence of disease. And then, how did the Believe Big idea come about? How did you end up birthing that organization?

Ivelisse Page: Yeah. So it was pretty much in two parts. So when Jimmy and I were at Hopkins waiting for our appointments, it was incredible to me to realize that not everyone had the support system that I had from my family and church and friends. And there were many people, Dr. Tims, that are alone and just sitting there. And I remember leaning over to Jimmy and I just said, "We have to do something. I think we're here for a reason, and we need to find a way to encourage them." And he said, "Yes, but what do we do?" And I went home and the next morning I actually was drinking coffee from a mug and I always took my kids to this paint your own pottery place. And I just always pulled out this same mug because it had their handprints on it and it always made me smile.

Ivelisse Page: And I said, "That's it. That's what we're going to do. We're going to have our friends and family paint these and just write somewhere on there the word 'believe' so that it would encourage those that are there to believe that they can get well, to believe that people in the community do care about them." And so we started to do that. And so believe mugs actually started Believe Big and throughout the appointments we deliver them. And now it's expanded nationwide to where people can walk into a pottery store and paint, and then they're delivered locally to patients in that area. And then as I went back for my follow up appointments at every three months for the first year, every six months for the next two years, I would talk to Dr. Diaz and say, "We need to do a trial on mistletoe. I am not the only one that's benefiting. And so many people need to hear about this. It needs to be made available." And it was up until the two year mark that he kept saying, "Ivelisse, I'm cautiously optimistic."

Ivelisse Page: And then at the two year mark, he's like, "Do you know how monumental this is?" He said, "All right, let's get working and let's start this clinical trial and then Believe Big was formed to kind of be the funding source to start raising the funds for the trial."

Dr. Lucas Tims: Yeah. It took him a while to come around. Yeah. And you see that with oncologists that they're reluctant to, if they know patients are doing something outside the standard of care to give much credence to it, but we have had some other patients in our experience like your case where it just becomes the ... It is so overwhelmingly obvious that the different path that patient's choosing is what's making the difference in some cases. And so, it's fun to see the oncologists come around, and it's interesting because, I think, when you and I first crossed paths was about eight years ago in Germany at a mistletoe symposium. And I know that was part of the origins of this monumental research that you guys have gotten involved with with Johns Hopkins, and so take us ... pass forward a little bit into when that whole project started and where it's at today.

Ivelisse Page: Yeah. So, we started having conversations with Hopkins and Dr. Hinderberger myself and my husband. We would sit down monthly for meetings and start to develop a team that would help to design the trial. And then we brought in researchers from Germany and Helixor, who is one of the mistletoe manufacturers in Europe. They agreed to provide the mistletoe for the trial and some of their experts also helped in the designing of it. And so, interestingly enough, a few years later, the trial, the FDA approved it to start and it was on December 24th the approval came through, and I was like, "How amazing that? The mistletoe trial got approved on December 24th." And so, the good news is it was completed in April and they're in the process of publishing the reports in the new journals of oncology. And so, hopefully within the next six months it'll be peer reviewed and published and then we can start in the phase two process of the trial.

Dr. Lucas Tims: So phase one, research, this is early stage research that's done in humans. I believe you guys had around 50 or 60 patients enrolled.

Ivelisse Page: Yes.

Dr. Lucas Tims: And interesting to note that they were treating them with IV mistletoe. Which is a little bit more of a recent development. For years and years, it was traditionally just given subcutaneously. I know that you did most of your mistletoe treatments subcutaneous, but more recent research. And now, with this Johns Hopkins research, we're looking at intravenous applications and could be even more promising, although the SubQ still works pretty good. Obviously it did for you, so exciting. And in phase one, that's just the first step, obviously. So, I think, it's important for people to understand that even though when that gets published, it's still likely that you're not going to be getting that mistletoe prescribed from your oncologist. But it's the first step in that ultimate process of getting through phase one, phase two, phase three, which can then lead to sort of full FDA approval, which is a lofty goal. But hey, one step at a time, right?

Ivelisse Page: One step at a time. And, I think, trying to think, what can we do for the patients of today? And we're so grateful for physicians like yourself that can still help patients with mistletoe, both avenues today. But the long term of this trial is so important to make it a part of standard of care and have insurance cover it. As you know, now everything's out of pocket. And so having this covered by insurance would be such a huge aid to patients that are confronted with a cancer diagnosis.

Dr. Lucas Tims: Yeah, no doubt. The fact that only some individuals are able to access this medicine is a real shame because of how ubiquitously it can be applied to the field of cancer care, whether it's in patients with active disease or prevention, secondary prevention, helping patients tolerate traditional treatments better. There's so many applications for it. And the fact that only a very small fraction of US cancer patients are able to access it both financially, and then some of them just don't aren't aware of it, right? Or there's not anybody in their area that offers it. And so we're getting there, but I mean, y'all's contributions – Believe Big, Johns Hopkins – that is the ultimate vehicle, how we get to that critical mass point where everyone can benefit from this medicine. And so kudos to you guys, your team.

Dr. Lucas Tims: I know it's been a long time coming and a lot of hard work's been put in, but thank you, on behalf of doctors like myself, patients, caregivers. We've seen the fruits of your labor on the front lines here with our patients, not only through the medicine, but through the grants that you guys give. I've painted a few Believe Big mugs myself at the local pottery place. I encourage everybody to do that in their area. We see the smiles that brings to patients. And so we love everything about what you guys do, and thank you for sharing your story with our listeners. It's very empowering and inspiring and keep up the good work. And we'll talk again soon down the road. Thanks so much for joining us today.

Ivelisse Page: Thank you for having me.

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