

[00:05:00] **Tiffany Wedekind:** I wasn't devastated or anything like that. I was more curious of like, well, what does that mean? Because I already saw my brother starting to decline and experience the effects of progeria at that time. So, but I wasn't declining at the same rate. So I was like, well, what does that mean?

[00:05:20] But, already at that point, I had already experienced a lot of trauma in life. So I had already had this mindset of, you know, acknowledge and move on. Trauma that I have experienced in my lifetime, I would say a lot of people have experienced these things. Unfortunately, I was one of them. When I was a little girl, I was handled in a way by an adult that I shouldn't have been.

[00:05:45] Right? I didn't know what was happening.

[00:06:14] But for some reason, when I got to an adult, And that changed, and I also experienced things, you know, on a traumatic level by someone putting their hands on me. How that happened, I don't know, but it happened. Right? And I almost lost my life. And it was just some random Joe Schmo that I just met in a bar.

[00:06:36] And he was able to do those kind of things and tell me that I was-- Because again, I didn't know that I had progeria. I had no explanation as to why I looked different, as to why I was different. And he told me I was a freak. And I was never gonna find anybody that was gonna accept me for being as different as I was.

[00:06:53] And I thought that was true. And I put up with it for about two and a half years, and experienced a lot of... I lost my innocence, that's for sure. I did not know how to handle that. That was scary.

[00:07:28] So I didn't trust anybody and I was like, God, everyone, there's a chance that anyone could do that to me. And I met somebody that just looked at me exactly the way I was and made me feel that it was okay and that I wasn't any of those things that that guy told me that I was. And regardless, you know, we've been in each other's lives, you know, for a very long time.

[00:07:55] But he was the one that really said, you know, not said it, but he presented that, you know, just by being himself. And allowing me to be myself. I wasn't afraid anymore. He gave me my confidence back, kind of. Cause I am somebody that does have all the reason in the world to be self conscious about a lot of things.

[00:08:21] And I don't pay attention to that. I just don't. I am what I am. I look the way I look. There's nothing I can do about it. I can hide the things, like me not having any hair anymore. I wear a wig, right? I have fake teeth. I don't have a voluptuous body. I am skinny and muscular. I'm lucky to be alive.

[00:08:57] **Stephen Calabria:** Let's talk about being a victim of domestic violence for a moment. Speaking from your own point of view, what goes through the mind of a domestic violence victim who's looking to escape? And why do you think so many folks try to tough it out through abusive relationships?

[00:09:19] **Tiffany Wedekind:** I am someone that gets attached and I am, I want to save the world kind of person, right? It's like, it doesn't happen overnight. It develops into patterns and then they say they're sorry. And then, you start to believe, like, Oh, well, yeah, you've had it rough. And I should just accept those things.

[00:10:08] Kids, people with progeria don't live to experience those kind of things, you know, typically not. So, I developed some sort of, you know, something from those experiences, and then I experienced it again later in life when I got married, but it didn't get so bad because I was like, nope, not doing this again.

[00:11:16]

[00:11:31] **Stephen Calabria:** You've talked about how you could draw upon your brother as an example of what could happen with the disease, so you weren't completely blindsided by the diagnosis. What did you observe with his diagnosis and what became of him?

[00:11:47] **Tiffany Wedekind:** Well, what I observed growing up of my brother developing with the issues that he started to have was, you know, in I would say junior high school, he had to stop wrestling because he had issues with the the curvature of his spine.

[00:12:02] At 19, he broke his femur bone playing basketball. A couple of years later, he broke the other one. Those never healed properly. And things like that started to happen. And then at 30, he had his chest cracked open, and I saw him gasping for air to try and recover for that.

[00:12:21] And, so, before he started to have to have a lot more surgery done, like his aortic, or his vessel in his belly, like, things like that. We got diagnosed,

but I had already started to see. I grew up with seeing things that now I had an explanation for it. Like, oh, this makes sense. Okay, so this is why it is why it is.

[00:12:47] So now I know. I'm seeing what is happening. I now see it with my mom. My mom has 23 stents in her body. She's had her aortic valve replaced recently. She had both of her hips replaced. She's had, you know, like, the list goes on.

[00:13:04] **Stephen Calabria:** She has progeria, as well.

[00:13:06] **Tiffany Wedekind:** Yes. Milder form, she's 74. However, those things didn't start developing until much later for her in her 40s? Mid, late 40s? Mid 50s?

[00:13:19] **Stephen Calabria:** And so, what became of your brother?

[00:13:22] **Tiffany Wedekind:** Eventually, at some point he developed a sore on his big toe on his left leg and it wasn't healing and they couldn't figure out why. And then they discovered that he had no blood flow to his feet, and then they discovered he had no blood flow in his legs, so they went to take his toe off. They ended up going all the way up above his knee, and it caused an infection and it killed him.

[00:13:51] **Stephen Calabria:** An important pillar of resilience is to find meaning and purpose in life. After you got your diagnosis, what did you do to enhance your meaning and purpose?

[00:14:03] **Tiffany Wedekind:** I dove into my creativity and my entrepreneurial spirit and drive like that, like wanting to be a small business owner. When my brother died, it really woke me up to the fact that I can't be the person anymore that works for someone else's dreams to come true. I can't do that anymore.

[00:14:27] And that really gave, my brother dying really gave me the courage to be like, no. I'm not doing this anymore and I'm going to try everything I can to make my own life the way I want it because I was starting to, not, I don't, I hate using the word decline, but break down, like, I don't know, my body started to experience things and at that time I was going through marital issues and I was like, you know, I think I'm just going to give up on this whole idea of what everything, everyone thinks life is and proceed with the way I think life is and the way I want it to be.

[00:15:07] So I quit working for the people that I was working for It wasn't a corporate job. They were small business owners, but you know, I decided to do my own business again and do my own thing and do it by being creative and making things that I knew that I could make or reaching out to people that I knew that could be a part of the process because Columbus is filled with creative people.

[00:15:33] So that's what I did. I was just like, Nope, this is what I want to do. And that's what I've been doing ever since. I got divorced and started my own business again.

[00:15:42] **Stephen Calabria:** Aside from your family, to whom did you look, especially after the diagnosis, as a role model?

[00:15:51] **Tiffany Wedekind:** Well, I would say growing up, even before my diagnosis, again, I wasn't diagnosed until I was 31, so by that moment, I had already experienced, you know, a lot of people.

[00:16:05] So, Madonna was one of those people that really influenced me because of her drive to succeed, her ability to create new things, and try new things. I think people like Carol Burnett, like comedians, people like that really spoke to me because I saw them doing things that I wanted to do.

[00:16:29] Not that I wanted to be famous or be a star, but they were funny and they were just a light for people that needed a light. And... Those were the two, you know, two, two people that I can think of off the top of my head that really just stuck in my, in my brain growing up to make me feel like, you know, it's okay to stick up for people when you know it's right. No matter what people say to you, if you know it's right, you know, do the right thing. And that's what I learned.

[00:17:01] **Stephen Calabria:** Do you see yourself as serving as a model for other people with progeria?

[00:17:11] **Tiffany Wedekind:** Yes and no. Because I have not developed like the typical person with progeria. So I have not suffered in the way that they do so early. I saw my brother suffer. Uh, I see my mom suffering. And I am here to say that. I, I do have, I have that circumstance, but I am trying to shed light on there is also a lot of other good going on.

[00:17:46] So people that do have those ailments or do have those struggles will be able to focus on other things during the interim, while you're getting over the

bad or while you're trying to process the struggle. That you think about the good things and have a perspective that is productive rather than hinders your way of life.

[00:18:16] **Stephen Calabria:** How much do you--

[00:18:19] **Tiffany Wedekind:** I can't relate to them on a level if that makes any sense. I can only relate by seeing because of my brother and experiencing the things that I experience. I'm not experiencing everything like that on their kind of level because I've been able to live my life like a normal person.

[00:18:41] Dichotomy, I guess, but I have. I've grown up, I went to high school, I went to prom, I got married, I had my heart broken, I did drugs, I ruined my credit, I repaired my credit, I built a business, I've had many jobs. You know what I mean? So, I can't relate to them on some level, because I wasn't struggling at five. I wasn't struggling to see at five years old, or worrying about having a heart attack. I didn't know anything about that, because I wasn't there.

[00:19:11] **Stephen Calabria:** What is your advice for young people suffering from progeria?

[00:19:20] **Tiffany Wedekind:** Enjoy all of the good stuff every day. When the bad stuff comes, just deal with it as it comes, but focus on the good. Focus on the good by, you find something that you like, experiment with life a little. Go out and explore things. Don't focus on the things that you're struggling with. Because you're gonna have good days and you're gonna have bad days. And just focus on the good days. And try and get into everything that you possibly can in life.

[00:19:56] **Stephen Calabria:** Let's talk a little bit more about the community here. So, it's also a very important part of resilience, social support, having people that have your back. So, our listeners can't see it, but we are surrounded by not just your art but that of so many people in Columbus and outside of Columbus. Talk a little bit about the creation of this community and how that helped you deal with living with progeria and how that was kind of an outgrowth of living with progeria.

[00:20:31] **Tiffany Wedekind:** Yes, so when I started my shop it was originally gonna be just my candles, which is a craft that I started recycled karma candles making candles out of beer wine and liquor bottles.

[00:20:46] I didn't want it to just be me. I wanted it to be other people that were creative and I know that a lot of beautiful things come out of pain and trauma and I wanted this to be a safe place for anyone to showcase their artwork or and specifically in Columbus in the surrounding areas so all of Ohio, you know, Ohio and Columbus-focused, and because I was trying to build something over here myself like I was doing it from scratch and that.

[00:21:23] I know that a lot of artists are afraid to put themselves out there, especially if they're like, Oh, this ain't gonna be good enough, no one's gonna want it. I'm like, okay, we'll just put it on the wall and see what happens. Right? And a lot of times it sells, and they're like, What? Like, yeah. So that, when that started happening, that's why I have a featured artist every month.

[00:21:39] You know, I want to give everybody in the community a chance to say, hey, this is what I make. That's why I do all sorts of art and music and Things like that. So I've created like a little hub where people like to come over and. Say hey, this is what I have and I do consignment and it just it works out nice and lots of people like the vibe That's going on over here.

[00:22:05] **Stephen Calabria:** In what way would you say that progeria is in part responsible for that?

[00:22:10] **Tiffany Wedekind:** Progeria? I don't think progeria is responsible for that.

[00:22:17] **Stephen Calabria:** Well, responsible, well, Tiffany is responsible for that. Your worldview was shaped in part by, by this disease.

[00:22:26] **Tiffany Wedekind:** Yeah, my perspective. Yeah, I would say my, yes, knowing that I have a limited time, I mean a lot of people have that concept, yes, but they don't. They're not paying attention to that. It sort of is just like a thought that passes by. I know that I have a limited time and that, I want, I try to encourage people to utilize their time in a productive way, in a purposeful way, and I really feel like my purpose was to help people be able to do those sort of things.

[00:23:00] Because of my disease, I am more aware of my mortality. So, I encourage people to, hey, take this moment and whatever it is that you want to make, just make it. If it doesn't work, make something else. Tomorrow might not be here, so it might not matter. If anyone likes it or not. So, just do it. Right? Fall in love with that person.



[00:23:26] Take a chance. Like, do whatever you want to do. But do it in a way productively. Because I have been through so many different experiences with trauma, with my disease. My disease has been traumatic for me in many ways. Getting my teeth pulled was traumatic for me. Imagine just having your face dug out most of your life.

[00:23:49] It's traumatic. So, I really just want to tell people, Hey, like, there are things that are going to come at you in life. But just roll with it. Just roll with it. Right?

[00:24:01] **Stephen Calabria:** In that vein, another pillar of resilience is realistic optimism, seeing things how they are with a clear eyed view and proceeding accordingly. What is your approach to that?

[00:24:16] **Tiffany Wedekind:** Being aware, acknowledging and moving on, not giving any energy to things that don't matter, Don't sweat the small stuff, in a sense. I am happy, every day that I wake up, I am happy for the opportunity to be able to create something new, connect to somebody, connect someone to somebody. I'm happy to be alive, and I have... That's pretty much what it is. I'm happy to be here. I'm happy to still be here.

[00:24:45] **Stephen Calabria:** To what extent would you say that your positive attitude and outlook is, is responsible for you having gotten this far?

[00:24:55] **Tiffany Wedekind:** Yes, it is huge. My personality has always been the same, no matter what my circumstance has been.

[00:25:03] I am still the same person that I've developed into be, and even when, just even, I remember being so happy as a kid and still things bad happened to me And I was still like would wake up every day and go, well, what am I gonna do today? Right? So I still have that same mentality of I have to see the good in the bad more so So I'm not succumbed by the bad.

[00:25:32] So my perspective is to see the good, or twist it around to make it good in some way. Especially when it comes to, you know, my experience with domestic violence. Did I want to experience that? No way, man. That was a nightmare. That's what nightmares are made out of. And I know it could be so much worse. That's my philosophy. I could have had it so much worse. And I got out of that, and some people don't, and some people die. So, it applies to much bigger things also.

[00:26:09] **Stephen Calabria:** You have every reason, to be embittered, to be negative. You've dealt with so much more than the average person has had to deal with. I got angry this morning making my breakfast. How did you not wind up, being embittered and angry at the world?

[00:26:28] **Tiffany Wedekind:** Well, because I know that just because I've had a bad experience doesn't mean that tomorrow's not going to be better if I make it to tomorrow, right? It is really hard to explain because I don't even know. Honestly, like, I get up and everything that, that has happened to me that's bad is not, that's not what's on my mind.

[00:26:54] **Stephen Calabria:** What's on your mind?

[00:26:55] **Tiffany Wedekind:** Creating things. Getting stuff done. I'm like, okay, well, I have this, this and this. Not that I have an order that I do things in because I, again, I have a, I have things that I suffer from that are a result of, now that we know, is a result of my disease. I can't sit still. I have, problems focusing, but I navigate it in a way where it's productive. If that makes any sense.

[00:27:23] **Stephen Calabria:** Of course that makes sense. You're focused on things other than pain.

[00:27:29] **Tiffany Wedekind:** Yes. I do not focus on what happened to me when I was a little girl, or what happened to me five years ago, or, you know, five minutes ago. I get over things very quickly. And I allow room for human behavior.

[00:27:45] **Stephen Calabria:** What do you mean by that?

[00:27:47] **Tiffany Wedekind:** Well, we all act differently. I mean, some of us, yes, it's the norm, there's a norm of the way people flow in life. You know, we get up, we get dressed, we eat, whatever, but our personalities and our way we handle our emotions, we're supposed to have emotions.

[00:28:04] We're supposed to be sad, we're supposed to be happy, we're supposed to be mad, we're supposed to be excited. We're supposed to experience all of those things. That's what helps us grow as people. And some people want to numb that. They're like, no, I don't want to, I don't want to feel that. I don't want to, I don't want to feel that.



[00:28:20] I don't want to acknowledge that. I just want to numb it down. I don't do that to myself. I let myself experience life for what it is. feel it. If I get sad, or if I get upset, or if I get depressed, then I let myself, and then I get over it, because I can't control those things.

[00:28:39] But I do, from my experience, the majority of people do the, not as woe is me, but they focus on the negative.

[00:28:50] They focus on replaying over and over and over again, festering about it. And I'm just like, Gah, I gotta figure out how to get rid of this. And the majority of the time it is creating something, coming down here making candles, going for a drive, getting on my Instagram and, you know, connecting people, or looking at things to get my creative process going,

[00:29:14] **Stephen Calabria:** Would you take it all away?

[00:29:16] **Tiffany Wedekind:** No, I wouldn't take anything away. I wouldn't be the person I am if I wasn't the person that I am. So if I worked so hard to try and be someone else my whole life, then no one's gonna know me. I let myself be unregulated. I get up when I get up. I start doing what I do. I also have to give myself forgiveness that I do have a disease and I forget that.

[00:29:42] So when I get up and I'm like, Wow, I don't feel good today, this sucks. And at first I'll be like, Nope, come on, like, get up, do it. And very little do I allow myself just to lay there and be like, Take a breather. Cause I don't want to. I'm like, I'm gonna miss something. I gotta get up. I don't feel that bad.

[00:30:03] It could be worse. like my brother, dying, essentially. And he knew he was gonna die. He told me he wasn't gonna make it to 39. And he didn't. I mean, when he said that, it wasn't soon after that he said that, that he died. So it's like, I pay attention to that stuff.

[00:30:27] **Stephen Calabria:** What are the biggest things that you still want to accomplish?

[00:30:32] **Tiffany Wedekind:** I don't know yet, whatever comes to my mind. That's what I want to experience. I already know the things that are out there that I could get myself into.

[00:30:40] But, you know, where do you start? You know, I mean, I've, I've been here for 45 years on this planet and I have experienced a lot. I did, I did climb a mountain. I climbed, uh, Mount Rainier out in Seattle, Washington. I

didn't climb the whole mountain, but I climbed as far as I could and came back down and said, I'm unstoppable.

[00:31:05] That's pretty much what happened because that was the time that I was trying to make the decision whether I was going to stay married for the sake of my stepdaughter or peace out. And when I got down off that mountain, I had no, no hesitation or no doubt that it was time for me to make change, hard change.

[00:31:26] And when my brother died, I really said, oh, what good, what good will come of that? Right? And I think lots of good has come of that because I chose to put myself out there on a love. I didn't want anybody to know I had progeria, to be honest with you. I was terrified of that because I already was experiencing issues with the public, questioning me and, you know, just questioning me about things, because I look different. And I just thought that would open up a whole new can of difficulties for me on a personal level. I don't know how else to explain that. But a friend of mine, Annette Grant, thank you very much.

[00:32:10] She convinced me to put that in my bio on Instagram. I was like, no, I don't want to do that. And she goes, just do it. And I did it. And two days later, or two weeks later is when a media group in the UK contacted me about doing a biography on me or a documentary on me. And then I knew that. Okay, I'm supposed to tell the world about who I am, what I have, who I am as a person, to show them that I was, I was given this circumstance, and I'm going to show you how I navigate it.

[00:32:52] And hopefully that will help other people navigate circumstances in their life. On a much more realistic and optimistic level.

[00:33:06] **Stephen Calabria:** That was basically it for my questions. Was there anything else you wanted to say?

[00:33:12] **Tiffany Wedekind:** No, thank you for having me.

[00:33:14] **Stephen Calabria:** It's our pleasure.

[00:33:15] **Tiffany Wedekind:** I'm happy to be here with you in my little studio.

[00:33:21] **Stephen Calabria:** Tiffany Wedekind is a Columbus, Ohio-based artist, candle maker, and survivor. That's all for this episode of Road to Resilience.

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