

Embrace Your Skin_ Stories of Strength

Wed, Nov 12, 2025 11:20:53 • 56:22

SUMMARY KEYWORDS

Prurigo Nodularis, skin condition, itching, mental health, clinical trials, dermatologists, support system, diagnosis, treatment, community outreach, NOWINCLUDED, black community, health platform, patient experience, skin health.

SPEAKERS

Rose Sherrod, Daricha, Tiwana

Rose Sherrod 11:21:15

You welcome. Welcome to the embrace the skin you're in stories of strength hosted by the NOWINCLUDED community. Hello. My name is Rosemary Sherrod, and I'm the Digital Community Engagement Specialist here and NOWINCLUDED. And NOWINCLUDED is a digital health platform, and we empower and educate communities of color to make informed health decisions. We have several health related community circles that you can join and connect with like minded people with similar health experiences. One is the hair and skin health circle NOWINCLUDED, it provides the information you need to keep your skin healthy. And you know what conditions that can affect the black community the most, and we'll drop that link in the chat in just a few for those of you who would like to join that community. So right now, if you're joining and listen, just drop, go ahead and just drop the city that you're joining from in the chat. And I have two amazing people that I'm just very excited tonight for you to meet the two very special people here with me today who are making a positive impact within the community. The name is Tiwana and Daricha, and I'll let them introduce themselves. Hey, Tiwana. Hey, Daricha, hi. I'll let you all introduce yourself, Tiwana, you'll go ahead. Hi.

Tiwana 11:23:05

So yeah, my name is Tiwana, and I live in Maryland. I'm a senior program manager for an E commerce organization, and I've been patient diagnosed with Prurigo Nodularis for just under three years. So looking forward to having this conversation with you all, sharing my story and getting to know Daricha in the process. Thanks for having me.

Rose Sherrod 11:23:29

Thank you so much, Daricha. Hi

Daricha 11:23:32

guys. My name is Daricha. I am an ICU travel nurse. I've been diagnosed with PN for a very long time. Mine's actually started in 2016 so since then, okay, and I'm excited to tell you guys my story and meeting Tiwana today.

Rose Sherrod 11:23:56

Thank you so much Daricha And Tiwana for introducing yourselves. Listen. Daricha has already shared her story on our NOWINCLUDED platform, and we'll share, we'll, we'll share that link in the chat for you all to watch more of her story. She has an amazing, powerful story of strength.

And so both of you mentioned that you were diagnosed with Prurigo Nodularis. If you would just explain a little bit, what is Prurigo Nodularis? Each of you,

Tiwana 11:24:28

I'll take that question, actually, sure, and I'm going to get a little medical I'm not a medical professional. I'm just a patient who has been surviving through this. But Prurigo Nodularis is a rare skin condition that exhibits itself on your body and presents itself on your body. Through these hard nodules, they could be either pink or red, the color of your skin dark brownish, almost turning black, all over your body in various areas. You know, it's different patient to patient. And the most critical symptom that I like to point out, and I'm sure Daricha has had the same experience, is it exhibits itself with intense, intense, intense itching, like relentless, unbearable itching, not chickenpox itching, but itching that sometimes you can't find any relief for so that's just a little bit of a Prurigo Nodularis is in a nutshell. Yeah.

Rose Sherrod 11:25:20

Thank you so much for sharing that Tiwana, because I know just a few people that I've spoken to, you know, in the hair, skin health community, or just a general community, they have they've never heard of Prurigo Nodularis, or some people call it. So thank you so much for explaining that, and if both of you would just share a little bit about your personal experiences with pn,

11:25:47

sure you want to go there. I'll

Daricha 11:25:51

go for me. Mark. Personal experience with being was the whole point of mine is because it was, like, right after high school, you know how you're ready to become an adult. So this is like, your icebreaker to, like, introducing yourself to the world being an adult, because we all pray for it. Well, not no more, because I got too much bills before I was like, so excited. And then out of nowhere, they actually started on my literally, the night, like two weeks prior to me going to prom I didn't even go to prom, because the way my dress was altered, my whole arms was out, and who was going to go to prom, like that. So I end up missing prom. So I started on my hands, and I'm like, Okay, what is this? Do you know how when you notice something, but your skin is usually always clear in high school, like, you didn't tell me nothing, like, what's the pimple? I did not have those okay in high school, yeah, so when I finally start getting on my arm, I'm okay. Maybe it's heat bumps, because I would get heat bumps. So I didn't really pay attention to it. It was when I first started college. I was like, okay, it literally in a blink of an eye, it went from my hands to my whole bilateral, whole arms, whole legs, full back, okay, so this is, like, it took over my whole body. And the thing is that what was frustrating is that you're going to these dermatologists, and they can't tell you what it is. You know, go to the hospital with a Okay, I got antibiotics for you. You going with a cut. Okay, let's sew it up. You know, like they couldn't tell me nothing. Then when you another thing that was frustrating is that you're getting to these dermatologists and you're like, um, it's itching, itching. It's itching. And they look at you with a straight face, stop itching. I cannot. Like, what do you? Are you serious? You're a dumb you're an MD. You are well aware that neurotransmitters were not control them, okay? Well, it's not like

I can tell myself. Just stop itching. And these itching, like Tiwana said this time my regular just, you know, itchy, itch. I had knives and scissors. I still have scars from the knife. Okay, to itch my skin, okay? So it was just, it was frustrating, not getting the help. And then everything you're trying, you go to natural remedies, everybody like, oh, just change how you eat. Okay, you change how you eat. Nothing. It just became frustrating me no longer being able to be the person I was, yeah, and so on. I'll give you a chance. For those of

Tiwana 11:28:33

you don't know, I'm really almost kind of meeting there is, I've met her a few times, but we really haven't shared the full length of our stories together. So it's really, it's really personal to hear how you've dealt with this, because we have a lot of similarities and we have some differences. I first have the first symptoms for myself as a full adult, you know. So you did this as a teenager, so I can only imagine the mental anguish you went through at that time. It was a pivotal time in your life. For me, it was right after covid. Well, covid was actually still taking place, and it started September 2021, and I just started scratching, like scratching profusely, like relentless scratching that I didn't understand what it was coming from. About a week later, all of these like nodules and spots and and blemishes just appeared. Now for me, they only appeared on the fronts of my legs, all over my back and on my arms. They didn't appear on my face, my chest, my hand, well, maybe a few of my hands, but for the most part, it was in areas that I was lucky enough that if I was dressed, you wouldn't even know I had. Pn, but the scratching and the itching and the presentation of the nodules was evident, and it was really unbearable, and I didn't know what it was. And this is the part where we do have similarities to Risha. I went to my PCP who said, I don't know what this is. Let me send you to the dermatology department. I spoke and met with several dermatologists, and they did not know what was wrong with me. They couldn't figure it out, and so you said something so key that that really tapped into me, was okay, well, what can I do about scratching? How can I stop scratching? I don't want to scratch, but it's unbearable. And I was given a little bit more. They did give me, like some topical creams and things like that, but it would do a temporary relief, and then maybe an hour or two later, I'm scratching again, so that it was unbearable to me. And so I went to several doctors, several dermatologists, who referred me to another dermatologist, who referred me to another dermatologist, and then finally, I got a dermatologist who is one of the renowned itch doctors. And I'm lucky enough, because being in Maryland, I'm not far from Baltimore, where Johns Hopkins is, I was lucky, but literally, until I got to him, 11 months later, did I find out that I had this thing? Called Prurigo Nodularis, and all I could say to myself was, jiggle what? What is that? I don't know what this is. I don't understand what this is. But like you said, Daricha, we couldn't figure out how to solve the problem until we had a solution. And so there was but so much that they can do when they don't know what it is. And that's what made it so hard for me, that first year of having pianist, since we didn't know what it was, we didn't know how to treat it, so that was a really hard time, not just physically, but that mental anguish that you go through, and I'm pulling and we're dealing with covid, where if you sneeze too hard, people were looking at you funny. Could you imagine being in public and scratching all over the over yourself, and I did the same thing as you did, Daricha, if it was a wall, a cup, I don't know, remote, I used anything near me to scratch because it wasn't topical on the top of your skin. You wanted to scratch to a point where you wanted to dig deep into your into your body, because that's how severe the edging

was. So it was a very difficult time for me as well, and I'm sorry that it had presented for you at such a pivotal time in your life.

Daricha 11:32:01

Yeah, it was. And the thing about it, because the nodules, as you know, they're like, so if anyone doesn't know, these bumps are not just like some you probably think, like, oh my god, it's just bumps. These are like, just imagine a tree bark, okay, like something like my background, it's very it's a bump with a hard crust on it, like we will, I mean, my mom, we will take the blade, like a little blade, and you can really cut the tip of it off, literally, like you're shaving a tree bark. So I just want you to have, like, a visual, okay, of how these nodules are. And then, yes, so I did actually try some steroids. But just remember, steroids, too much steroids. So for me, I was getting into like an overdose phase. So instead of it like helping, it was causing more harm to me. So I had to stop it. Then to imagine so you could literally have, like, a game, like crisscross, I mean, like 20 people could just be on my body, connecting the dots. Okay, so just imagine I found one dermatologist. Mind you, I go to dermatologist here in Miami, West Palm Beach, wayton Beach, Orlando, Tampa, everywhere you can think of. I even went out of the country to my homeland, in Haiti for treatment. So we went to to find treatment. I found one dermatologist. This man was taking the corticosteroids, and he was inject, injecting each nodule every week, inside the nodules, and with a needle inside every week too. So it would be him and his assistant, PA, just sitting around and just injected, injecting as much as they can every appointment. So just imagine, okay,

Tiwana 11:33:44

it was, and did you have, like, I had this at some point. And as you're explaining about the bark, it's what it would be the equivalent to, like the layman, to say, these huge scabs all over your body. So the nodules would appear. And then for me, a scab would be created on top of it. And then sometimes the scabs would fall off and bleed like this is how severe it was for me as well. So they would literally bleed. And then you couldn't scratch them, but they were still itching at that point, I could not scratch it because it was now bleeding. The skin is an open wound. I had to sometimes wrap myself in like medical gauze and band aids just to cover and keep it clean so that it didn't get infected. But the itching never stopped, even though we I'm going through this process of these and, you know, we call them nodules, but they literally were scabs. Yeah, they were literally scabs. And they were huge scabs. And sometimes they normally circular, but they could also be a little oblong, so it would look like someone, just like, scratched me across my legs, and then that becomes a scab, and then that scab falls off and it tries to heal, and it's just an ongoing, repetitive process. It was so difficult to deal with. It was so difficult to deal with, yeah, man,

Daricha 11:34:59

it's like, now I'm thinking about it. It's like, because now I have the myths, I have the health care background, so now I'm a little more aware. But just imagine, back then, all these open nodules. I could have been prone to infection. Infection could have left sepsis. I could have died like 100% you know, and not only just the health aspect mentally, you know. So I wanted to ask, like, Did it affect how you dress or anything for you? It

Tiwana 11:35:26

affected my life in so many ways. That's a great question. It affected me to the point, you know, I'm sure, and I'm a little sticky. I like to have my little legs out. You know, I like to be cute. I don't wear my legs out anymore. I wear pants leggings, and if I do wear a skirt or dress, it's a maxi down in my ankles, and I'm not even that tall, you know? It affects the way that I dress. It affects my daily life. It affects my vacation life. I'm a beach bum. I love a beach. Beach. Now it took me several years because, you know, the pandemic had hit. This took place right at the tail end when we were just, like, getting vaccinated and things like that. So I wasn't going to the beach and I wasn't going to public places, because I'm also a bonafide self certified germaphobe, so I thought it was almost a remnant of the covid, like a new symptom of the covid at one point. So I don't go to the beach. So it's changed that. And when I finally started going to the beach, I only go to the beach if I can wear, you know, those sheer pants that you put over your bathing suit. I won't wear my legs out because, so can you imagine being out at the beach, and, yeah, and, I mean, in the water and everything, I keep the pants on in the water. So it's affected that. And it's also effective dating. It's a conversation. When you decide to get into an intimate relationship with someone, they're going to see this, and they need to, you know, rightfully so, they're going to ask questions. So having those uncomfortable conversations is another way that is completely changes the way that you deal with this every day. So those are just a few ways for you. Was it a change for you?

Daricha 11:36:57

So mind you, remember, I was just coming out of high school in high like that, like, I had so many friends, and the girls went like, you know, they was just haters, but, you know, I had a lot of friends. I had a lot of friends. I was always going out partying. I always had the little shorts, the, you know, the crop talks like, man, that's right, I went from being that girl full of life, always laughing, to like this girl who was like in the ball. So I live in Miami, so just imagine I was always, you would never catch me without a jean jacket. I had a I wore jean jacket so much I have like an imprint in my arm. Yeah, I believe you from wearing jackets so much in the heat. Okay, people like girl, take that jacket off. You're not hot. I'm like girl, just like every time you go to the stores. And like people in this world are just so mean, you don't know that. I didn't. I don't have nobody. Everybody in my family has beautiful skin, clear skin, not a pimple in sight. So the same way I woke up with it, you can wake up with it too. So we need to sometimes consider we don't have to be so mean all the time, like, yeah, look at you. Like you some type of zombie off of Walking Dead. And it's like, at least hide it, like walking or and then you could talk, but right in my face. So it was just, it came SOP, I did not go outside. You couldn't

Tiwana 11:38:16

keep thing that you just mentioned is the kindness of people. You had a situation where you were just coming out of high school, these, these big events, your prom, and all this good stuff. And then I was coming from covid, covid. Now I understand that people were very sensitive around covid, but what I want people to also learn about this. This is not a contagious disease. It's not a communicative disease. You can't get PN from being near me. You can't get PN from being near Daricha. However, it does run a little more rampant in the black community, so it

could be anybody, if you have underlying diseases and you from a medical perspective, share, you know, tell me if I'm if you have underlined other diseases, high blood pressure, type, other things like that, you could be more susceptible to it. So like Daricha said, be kind to people. You may not know why they're scratching. You may not know why all these things are presenting all over their body. But if it really bothers you, it's easier to just walk away. You don't always have to look at them like, what are you? And then I know what you mean. If I'm in at a restaurant and I'm scratching because I can't help it, I'm quite sure it makes someone feel uncomfortable. But if you feel uncomfortable watching me, how do you think I feel doing it? I feel worse than you do. You're just looking at me do it. So how do you think it makes me feel? So I think that is a very good point that we need to make, is be kind to people, and if it bothers you that much, you can also walk away.

Daricha 11:39:40

Yeah, and the thing with everybody, there's just so I wouldn't say I don't like to use the word ignorant. I would like to say they're not educated, right? To realize that no one wants to do certain things because they want to sometimes, we have no control over the things that we do sometimes. And you know, some misconceptions like you said, is that, oh, it's contagious, like it was. I had a cousin actually had a newborn baby. Oh, my God, we never forget this. I cried. She would not let me hold her baby. Oh,

Tiwana 11:40:11

my goodness, because she felt like maybe it was a contagious situation. And then,

Daricha 11:40:16

like, so when she came to my grandma house with the baby, you know, my grandma had the baby, so I took the baby, she like, Oh, give me the like, she didn't even try to hide it. She was just like, give

Tiwana 11:40:26

me the have a clear understanding of what your condition was. Had you had conversations with your family

Daricha 11:40:31

about it, I couldn't. How can I have conversation about something I don't know about? So that's how this was during the time when you weren't diagnosed, yet I wasn't diagnosed. So I prior, you know why I've been diagnosed? You couldn't tell me nothing like I knew what I had I was, you know, that's why I don't let some right now in my mental state, because back then, when it come. Was about to ask you about that I was depressed. I would not leave the house, I would not do anything. And then what made it worse is like seeing my mom cry, you know, because she can't help me. You know, Mother, I always feel like their child should be able to go for it may help, but my mom couldn't help me. She didn't know what to do. I know I could only she would like try to get me out of the house. I would not want to go nowhere. I didn't want to go anywhere either. I became obese, like, morally obese, like, just because all I would do is sit in the house, right, watch Walking Dead and eat literally,

Tiwana 11:41:25

yeah, but that's a point that you make, that I think we both touched upon, is that people don't realize it's not just a medical physical, you know, condition that we're going through, there's a mental aspect to this. And I know that, you know, I've been a germaphobe for a long time, so when covid came, you didn't see Tiwana. Tiwana to walk into a grocery store for like, 18 months. I didn't walk into a pharmacy. Everything was dropped, delivered to my door, because I didn't want to be around humans. So imagine now towards September 2021 where we're just starting to comfortably get out of covid. This thing happens to a germaphobe after a pandemic. My mental my lack of mental health was through the roof. I was so depressed, so I know exactly what you're talking about. And when you go through that period of not knowing what it is that is one of the toughest phases that you go through because of look at the situation you just have with your family member. Oh, don't touch my baby. Oh, I don't want you near anybody. I don't want you to come. Do you know what that does to a person, how that makes a person feel? So people need to recognize, especially even in the medical field, when they are assessing what this thing is, what this condition is, they need to also pay attention to the mental health aspect, because if you are not okay mentally, or you're not coping well, mentally, your body reacts to all of that. Your body reacts so when you think about the day when you're stressed, you get headaches, you don't feel that your stomach hurts. So not having yourself be in a very strong mental state doesn't help the disease either. It doesn't help us get better. So that's I'm sorry you had to deal with that. I think I've had some looks, but I've never had to deal with a family member not wanting to be near me or have their kids near me because of it. So that's deep

Daricha 11:43:13

it was, it was just very bad, and like, when it came to mental, it came to a point where I didn't want to seek treatment. Like I was like, this is just your new life. I was over. Because, just imagine, everywhere you go, you go into doctors, dermatologists, like, for over 12 years, and they can't tell me what it is like at this point, why am I still going for me to as soon as I walk in, I'm like, Okay, God, maybe I'll find a treatment. And then, boom, I don't know what that is. Daricha, I cannot help you. I'm gonna send you somewhere else. I was just tired of I'm gonna send you somewhere. I'm gonna refer you to a specialist. And then when you get to the specialist, they don't know what they do. They don't know what it is, you know, so you feel

Tiwana 11:43:55

like they weren't really trying to help you, or they just wanted to pass you over.

Daricha 11:43:59

I think some Okay, when it comes to physicians, some like dermatologists, especially the ones who feel like they know so much, when they get to seeing certain type of things that they can't diagnose, they misdiagnose you, right? So I've got bedbugs. Yeah, I've got heard that one. Yeah, I can see why. And I'm like, I have never seen a bedbug in my life. Now I have because I'm a nurse and people come in without but I have never seen a bedbug in my life. So for you to come and tell me it's a bedbug, it's like, sir, no, this is not a bedbug. This is not bedbugs. I never been around that, but I don't know how that books look. And then you'll have the ones who's

like, Oh, these are just like eczema, you know. Eczema, you know, shows itself in different forms, you know, so eczema. But then when I'm googling these things, I don't see nothing that look like me. No one like me, so this can't be what you're

Tiwana 11:44:56

telling me it is, right? And I think about all of the labs that they sent me for multiple times, I remember the first dermatologist was like, I'm not sure what this is. He didn't misdiagnose me, but he didn't know what it was, but he did say to me, I don't think this is eczema. There's something else going on, but I'm not sure. Let's run some tests. Let's see. We can figure out what's going on. Can you imagine, I was sent for test for lymphoma, hepatitis, HIV, they thought they were lesions to AIDS, so all the tests came back negative. He was like, I don't know what this is. I'm gonna take you to the next level dermatologist. He did the same thing. He assessed everything. He sent me again. He was like, I don't know. I think I want to send you again for HIV. I was like, first of all, in these damn covid streets, ain't nobody, ain't nothing going up in the ring. However, I could understand. I still wanted to know what it was. Every I was tested over and over again, they wanted. To send me to an oncologist. They thought I had skin cancer. So could you imagine what I was what what I was thinking with my brain? Okay, so I'm sitting back at home waiting for you to tell me whether or not I have HIV, whether or not I have cancer, whether or not I have lymphoma. I was scared. They almost thought I had leukemia at one point, like adult leukemia, it's frightening to have a condition that is so rarely diagnosed properly that you don't know what to do in the interim of not knowing what you have. Yeah, it's it's scary and life changing.

Daricha 11:46:28

Very Yes, it is. And I wanted to ask you, like, when you see, like, for me, I had, like, my mom, my sisters, did you have, like, any support system

Tiwana 11:46:37

around at least? Great question. When I first noticed the nodules, it was the first time I'd seen my mother in 19 months after covid, and I had come out the shower, and I pulled my and I was drying my back, and my mother saw my back. And she was like, she was like, What is that on your back? I didn't even know that I had all of that on my back. I know my back itched a lot, but there are also, I don't know if this happens too. They're also areas on your body that don't have nodules, but still itch, because it's almost like it's in your blood. It's like my scalp itch, but I have none in my scalp. But I say all that to say, the first time I realized some of the symptoms I had, I was lucky enough to have my mother there here, who there with me, who doesn't live here. She lives in North Carolina. She come to visit me for the first time after covid, and ever since, I've been sharing with my family what's going on with me, and they have been incredibly supportive. I am lucky. I do have them. I don't have any of them physically here in Maryland with me. They're all, you know, in different parts of the country, but you know, just checking in to see if I'm okay makes a big difference, making sure that, you know, Hey, how's, how's your pan been? Like, they don't fully understand it, but they care enough to try to figure it out. And that support means everything. It means everything. I know you had your mom. Did you have any other support factors? Because I know I'm also trying to get more involved in community outreach and

things like that, to build more of a support system for myself as well share for others. But do you have anyone outside of your mother who supports you?

Daricha 11:48:08

Well, right prior, I had just my mom and my sisters, because I was not opening up, and that's all I would like to say. Dealing with something, don't keep it into yourself. Yeah, you know, really take the load off. You know, have people support you and help you. Because without my mom, like at this point, when they did tell me, oh, maybe a skin cancer, I was like, okay, cancer. I'm ready for you to take me out. I'm ready for you to take me out at this point, because I couldn't deal with it no more mentally, you know. And right now, I, like you said, for dating, you know, I'm thankful to have someone now that doesn't judge me, even prior to seeing, like, the pictures I've dealt with, he doesn't judge me. He doesn't make me feel the type of way, but beautiful. Before I could even open myself to dating again, it's like, okay, what he's gonna think like when he see me with, like, without, because I'm always covered up. So when he sees my What is he gonna think? So a boy would y'all talk to me? I'm running like, I do not want to talk. I do not want to say nothing to you, you know. So it was like,

Tiwana 11:49:10

so, you know, you're gonna have to have that conversation that I'm not ready to have.

Daricha 11:49:14

I'm not ready. Yes, what is this? Yeah, based off something I can't control, you know? So it took a toll, like, so for now, are you like open to try to

Tiwana 11:49:25

honey, absolutely bring them on

11:49:32

limit. You like these?

Tiwana 11:49:35

It did for a while. I think I felt a lot like you. I think the biggest part for me, I guess that made it just slightly different. The lack of dating was a lot because I was remote, and I was, you know, quarantined off from people. And even after people were going out in the streets, I wasn't so it's hard to meet somebody when you're still in the house. You know, you have online dating apps and things like that. But I really wasn't putting myself out there like that, because it took me a lot longer to be comfortable with being around people than than the average person. But mentally, it took a toll for a while. But now I'm 100% open, because I feel like, especially, I know I'm a little older than you. But I really feel like, especially at this age, if I'm going to meet a man at my age who is not mature enough to have the conversation with me and accept me as I am, then I don't need them, and that's okay, you know what I mean? Like I would wouldn't want to invite anyone into my space who didn't have the level of of maturity to say, oh my gosh, I'm sorry you're going through this. It shouldn't make me any less of a person. Either I'm a good person or I'm not, and

I wouldn't want someone who was solely just not want to be with me just because of what I look like. Yeah, hopefully I

Daricha 11:50:52

have a question. So when you were diagnosed, when you finally got a name, Prurigo Nodularis, how did it make you feel? I

Tiwana 11:51:00

will tell you exactly how I felt. My doctor actually walked in and he asked me if he would mind if he brought a team of doctors in with me. I was like, What am I about to die tomorrow? Like, what is happening here? So that scared the living daylights out of me. But he was training some fellow medical students, and I thought to myself, well, how are they going to learn, you know what I mean, if they don't become a part of a conversation? So just the dramatics of them walking in, he came in, and he said to one, I've looked at all your labs, all of the previous doctor's notes. I've looked at your blood work, and you do not have cancer. You do all of the other tests have come back negative. But after looking at some of the blood cultures and things like that, we finally figured out what you have. You have a risk in disease called Prurigo Nodularis. Soon as he said that I didn't hear anything else, he said it was like Charlie what Charlie Brown's teacher won't go more I didn't I heard white noise, because after 11 months of dealing with this thing that I didn't know what it was, I couldn't even receive the additional information he was giving me, because all I kept saying to myself was, It has a name. What I have has a name. I remember getting very emotional. I'm feeling it right now, but I remember almost crying because I was sitting here like this man gave my condition a name, and like I said before, because we didn't know what it was, everything that they tried to treat me was a toss up. You didn't know if it was going to work the top you didn't know if it was going to work. They gave me some orals. You didn't know if it was going to work because they didn't know what it was, yeah. So finally, now we have a name. Now we can make a plan, yeah? So I was elated, but I promise you, I literally went back to him and was like, Yeah, doctor, Imma, need you to repeat all the words you just said, because I was in another state of being so happy that I finally have a name to what this condition is.

Daricha 11:52:59

Yeah, I felt the same for me. Actually, they did a biopsy, so finally, okay, after dozen, like a dozen of dermatologists this one because, because my story was a little crazy ish. So one day, my mom end up just like, bleeding out her eye, like from a movie. Things you see in a movie, listen, like, I this is, I wish I could bring the call her. I literally just start bleeding. Okay, so I live in Miami, so there's, like this eye institution, okay, Boston Palmer, okay, in Miami. So the amyloids came. We ended up rushing her there while I was there. And I just feel like, well, I'm like, a spiritual person, so I just feel like everything happens for a reason, and sometime we're being used for a purpose. And I just felt like this was my purpose to help other people. So when I finally got to the emergency room, I see this big sign, like, Oh, um, skin if you have a skin condition, there's, like, a skin trial. Come join us. You know, any wear conditions? I'm like, okay, you know, at this point, I was like, done with it. I was like, This is my new life. I'm going to deal with it. So when I first seen the sign, I ignored the sign. I'm like, don't already got time, but I'm

not going to put myself in that again where you get hope, and it's like, it's took it right away from you. So I'm not going to call. I'm not the second day I came that sign is like, now from the side of the emergency room, it's like, right in the front now. So I'm like, Okay, why is this sign like? Every time I come in, the sign is getting closer. Forget it. So the dermatologist didn't let me go walk. You can actually walk to the dermatologist office. So I end up going, they end up doing a biopsy. So they do the biopsy, um, mind you, when they do a biopsy, guys, so they're injecting it, okay, with like topical, like, anesthesia, okay, so you don't feel it, and then it literally dig the whole nodule out the testing, so they're going to take the whole bump out, so now you're left with like, a hole in your skin. I believe, like, two weeks passed and they're like, Hey, can you come into the office? So I'm like, I'm coming in the office. In my head, there's a million things going on. Okay, of course, what is this thing? What are they going to tell me? Are they going to tell me they can't find it? So I didn't go in happy. I didn't go inside neither. I went in with a flat effect, because I didn't really care anymore. It was like, it is what it is. So why they told me? PM, oh, I felt like a whole sense of relief because, like, I didn't get diagnosed to, like,

Tiwana 11:55:47

four years. Oh my gosh, there was less than a year for me, and I thought I was going to fall apart. I can't imagine four years.

Daricha 11:55:54

It was four years. Okay, so when he said Prurigo nodular, I'm like, I don't even care how to pronounce it. I have a name now. Okay, so I'm like, can you tell me what it is? So he was explaining it to me, what it is, and I'm like, Okay, I don't even care what it is. Can you help me? What can we do now? What can we do? So they started clinical trial where they like, try, I guess, like, different medication, whether it was a medication or placebo, to see how to help. And from there, I slowly felt like diverse should coming back. Yeah, it was who you are, relief. And I always tell people, like, when it's storming, it's not going to rain for long. Has to come back out. And for me, like, oh my god, from there again. Like I was, I was mean,

Tiwana 11:56:43

and this is so like, your story is beyond touching, and it's so much the reason why I do things like this, that's exactly why? Because I know just for the year that it took for me to get diagnosed, and you're telling me four years for you, I the the mental anguish that you must have been going through still not knowing what's wrong with you for four years. This is why I do this. This is why I want to be so much closer to our community. I want to share with people what this feels like what it there are so many degrees of it, like I look at you. You are gorgeous. I look at you and I think about the fact that you did say you had someone your face. Look at you today. Look at you right now. I've been blessed enough where there's always someone worse off than you. It never appeared on my face. I'm lucky. And there are people walking around with it all over their face, all over their neck, all over their arms and hands. You dealt with that, you know what I mean, and I can I feel uncomfortable with what I deal with. So imagine the degrees that other people are feeling, how it makes them feel. So there's anything in my story can share. I know you shared your story multitudes of times, and I commend you for that, because it's not always easy to be this transparent and to let people know how it makes us feel. But if I can help

one person who's dealing with PM, or I can share my story enough with a with a medical professional so they know how to diagnose it better. They know how to handle and care for their patients better. They know to ask more questions about itching, to help people kind of work through make sure you're checking in on the mentally, how you feeling today, what's going on, how you good? These are all important parts of the medical examination when they're looking at these nodules, because it's so much more than just the scars. It's a mental scars that can hold you can hold on to for a lot longer than these physical scars. And it's so important that we keep getting the word out about it.

Daricha 11:58:39

Yeah, we have to because and even the case. So, like some dermatologists, you know, understand, try to understand your patients when they come to you and they tell you, because pain, you can't, you can't measure pain. You can't you can't go through an MRI. You can't see you can't see you can't do extra you can't even do an EEG to literally put electrons to checkpoint to tell you how much pain I am. So if I'm telling you I'm in pain, whether it's 1000 out of 10, you need to believe your patient. You need to figure out a solution. I don't take drugs. You could do a urine analysis. You're not going to find anything in my urine. So if I'm telling you I'm in pain, I don't have no psych issues. You need to believe your patience.

11:59:16

Yeah, so important. Yeah, I'm

Rose Sherrod 11:59:22

not going to get emotional. We said a lot. We said a lot today, not, yeah, not going to do it to me. But listen, first, I just want to say thank you both for being so transparent and sharing your stories, your experiences on our platform. I'm very grateful for both of you, just for being strong black women and strong black women that have endured such a trial, and you coming out on top, like you're thriving. And so I just want to say I appreciate you both, we're going to open up for for questions in just a moment. I just have a couple of questions. So if you have questions, those who are watching drop your your questions in the chat. But I just wanted to, want to just say, like, what tips or advice would you give to someone that may be experiencing those type of symptoms, they may be experiencing those type of symptoms, or have PM, what would you? What type of type of advice would you? Would you give them? And then I just have one more question, and then we're going to Q and A, okay, you

12:00:30

want to go first? Yeah,

Tiwana 12:00:32

I would just definitely say I know that we, both myself and Daricha, have had different experiences with our dermatologists, but do not stop telling them. Keep telling them what you're dealing with. Share that you think it may be pn, I know people doctors don't like for folks to self diagnose themselves, but Pn is not as it's getting more. Action Now, then I know that it was when Daricha was first, you know, diagnosed, but it's still a rare disease. It's still a rare skin

condition. So make sure you are constantly telling them. Take a look at this. Please pay attention to my itch. Do not stop telling your doctors, even if they're not giving you as much attention as you need go to another one. If Daricha said, after the first doctor, I'm not going to see any more doctors, she never would have gotten to today. She went to another doctor and another doctor and another doctor, never stop advocating for yourself. That's probably the best advice I can give anyone. Hopefully you're lucky enough to get with dermatologists who are like, we're going to figure this out. And I was lucky enough to have that that's not everybody's situation. So if you're not getting the care of the answers you need, keep pushing. Go get a second opinion, a third, fourth, fifth, until someone figures out what's going on with you. And take a mental health check every now and then. Make sure you have a good support system behind you, because you're going to need it. If you have it, you're going to need

Daricha 12:01:54

it. I agree everything you say, I agree. And I second that I would also want to say, when you're dealing with this, don't lose hope, because just imagine if I didn't call, I wouldn't be where I'm at today. And let's just say you can't you're done. You can't find a dermatologist in your area. So what if this is your new norm? Okay? You have to be your own individual. You have to be your own person. Somehow, whether this is going to make you stand out, okay, like even if it causes attraction, I wish I was strong enough in the past instead of hiding, to embrace the new me, to embrace my skin, because at the end of the day, I can't control it. So why allow something to take over my life? Why allow so? I just want to say, like, don't ever lose hope. Don't fall into, like, the trap of depressions, because you will lose on so much. I dropped out of nursing school. I would have been far because my goal is, like, to be a CRNA. So because I, like, dropped out of school because of it, like, I was pushed back. You know, right? You shouldn't let something like your skin take so much control over your life. Yeah, it's hard, but we just have to, you know, stay positive and like, keep pushing, keep going, whether it's not a skin condition, whether it's a health condition. Well, whatever it is, keep going. Just keep going. I don't care if you you lose your feet bilateral legs, you're going to get on the wood train. Keep going. Like, just keep going. That's, that's, that would be my advice. Just keep going.

Rose Sherrod 12:03:28

Yeah, listen, you have encouraged me. If you have not encouraged anyone else is it was me. So I'm going to keep Thank you. So in my last question, I just wanted to to know like, what are your What are both of your perceptions on clinical research? Have you ever been offered the opportunity to participate? Would you ever participate? You know, what are your perceptions around clinical research.

Tiwana 12:03:56

Okay, I'll go. I was actually a part of a clinical trial that was life changing for me. I can't give the name of it, because it's still not on the market yet, but it, when I say life changing, it was supposed to work on the blemishes as well as the itch. The blemishes have gotten a little better, but the itch is night and day, and that, to me, was the bigger deal, because the blemishes, I can cover up, blemishes I can't stop scratching. If my brain like, like you said, my brain says, scratch your skin off. That's what my what my body's going to want to do. So when I did get on the

clinical trial, it took, it was, I think it was instantaneous. I truly believe myself that the first three months was an 11 month, which is ironic, because it took 11 months for diagnosing, but it was an 11 month trial, and I believe the first three months you either get the placebo or you get the real medicine. I think I got the real medicine. There was an instantaneous change in my body, an instantaneous change in the amount of itching, an amount of scratching that I exhibited, and it just got better and better and better. An additional part of the trial was you had a little app that you had to go to each day to talk about your pain level and your itch level. And that was great, because what I would use that information for was I would say, Okay, did I eat something different? Did I do something different? Because today I was very itchy with the most part. I could just literally see it gradually, just declining. So it was really great. I thought it was a good idea for me to be a part of the trial also, not only just for the relief that I got out of it, but I also thought it was a good reason to be a part of trial, because I'm black, and I think we need the input. We need the input on how it's affecting black people. So having that kind of demographic for them to work with only helps benefit. Because we're as black people, we're so much more prone to. Certain diseases and ailments than other demographics. So I thought it was important for me to be a part of it. And not only am I glad that I did it for our community, I'm glad I did it, because I definitely got some relief. So yeah, I'm a proponent. I'm an advocate for clinical trial do your research, because I did too before I did it. I'm an advocate for that, as long as you make sure you do your research, that's good. Thank you for sharing.

Daricha 12:06:17

Daricha, I am too. I would say go for it, especially like, because sometimes doing the research on the clinical trial, there's not really much you can find. So once you get to them, ask them, like, okay, what are the side effects? Sometimes they don't, even though they don't know. But it's like, lose you know, even if it don't help, even if it do it, just try it. Give it a try. Because you what you want to do. You're not losing like just give go for it, go for it and stay positive. Because the more you think negative, you're remember the power of the tongue is powerful. So if you speak negativity in it, you're going to bring negativity in it. If you speak positivity to it, you're going to bring positive. So when I actually started my clinical trial and I seen I was like, Okay, this is gonna work. Like, I was like, I was happy you got to I was happy to leave the house. And, like, even now, like, if they asked me, Hey, you want to come in another clinical trial? Yeah? Like, I'm going, like, I'm gonna go, you know, because it's like, why not give it a

Tiwana 12:07:12

try? Yeah. And you have to also, like we've said throughout this entire webinar, you it's hard, it's better. It's easier said than done, but as much as you can, you have to believe it will be better. You have to believe it'll be better, even if that times you're like, I'm dealing with this bull, and it's not things are not getting better. If you stay in that negative space, your body will react to it, and you won't be better. So you have to go in with the highest degree of positivity as you can. And it's going to be a journey. It may not be immediate, it may take months, it may take years, but you have to believe that you are doing the best that you can to get the results that you want put, I mean, I'm serious. I know it sounds very cliché, put that positive energy out there, because it will make all the difference, not only in your body's reaction to it, but also your peace of mind,

and how you're able to flow and flow through each day. With being in that space is going to make a difference in your recovery. That's just how I feel, 100%

Daricha 12:08:14

No, it is 100% because I just wanted to, no, no, no, no,

Rose Sherrod 12:08:18

you get because I'm listening to both of y'all. I love, love, love the feedback. And I just want to say, so what would you say to people, especially black people, that are hesitant, right, or fearful? I've heard people say, Oh, they're not experimenting on me, you know, stuff like that. Like, what would you say to people that have fear? And I think you already said it when you say, go into it with a positive mindset. But do you have any other advice for people that are afraid or uncertain?

Daricha 12:08:45

You want to go first, honestly, sometimes you have to fear is okay. It's okay to be scared, sometimes natural the more you're scared, because sometimes that fear is put into you, because it's like greatness is about to come. Okay, so it's okay to walk into something being scared, the more you're scared, you let that take over and encourage you to keep going. Okay, so it's okay to be scared. I mean, it's new. It's like, you don't know what they're injected into you. You're about to happen. I get it. Okay, I do get it. But you just have to put in your mind and be open to I need something that's going to help me. And I'm going to do whatever it is to bring the person I was back.

Tiwana 12:09:32

Okay? I would agree, and I would add to everything she just said, plus one for sure. But like, we are always in constant fear of things, and that is a natural thing, but I agree we have to believe as best as we can. And like I said, when I say, the research make sure you're dealing with a reputable medical organization things like that, because when you do a trial, you really don't know everything that's in it. They tell you what's in it, but you don't know what those medical terms are. You don't know what that what it is, but if you never try, how are you going to know? If you don't try, how are you going to know? And you may try something and it may not work out, but that's okay, because you know what? There are 100 other things that we can figure out, but never stop believing that you are worth it. You are worth doing everything you can to be the best you that you can be, no matter what your ailment is. It doesn't have to be. Pn, it could be anything. Why do you think you're not worth it as much as you may be afraid and we all are because I was scared. Many, many moments, many, many moments throughout this whole journey. But why are you not worth it? Why would you not do that for yourself? Because you know what you would do. You would push your family member, your mama, your daddy and everybody else to do it. Why would you do

Rose Sherrod 12:10:46

it for you? Yeah, no, that's good.

Tiwana 12:10:50

Have to believe you're worth it because you are. Because you are

Rose Sherrod 12:10:54

I love it. I'm going to sleep good tonight. After talking, I feel like I've been to church a little bit. So listen, we have two, two questions that we're going to that we have from the community. Let me see. Sorry. I'm trying to get my my

12:11:15

screen up. Oh yeah, I can see it.

Rose Sherrod 12:11:18

Okay. There we go. So are are we, as we are listening to your stories, especially around diagnosis, what do you think are things that's needed to transform how dermatologists treat Prurigo Nodularis, and that's coming from Candice.

12:11:37

Great question. Candace, I actually spoke at one of the

Tiwana 12:11:45

American associations for dermatology, and that was a question that they posed in the first thing that came to mind was concentrate on not just what the patient looks like, but what the patient is telling you. I think some of the dermatologists that I spoke with the first few until I got to my diagnosis doctor, they weren't paying attention to the fact that I'm scratching like crazy. I think Demetrius derisha said it when she was like, stop the doctor said, Stop scratching. How am I supposed to do that when the itch is relentless? So I think what was happening at the beginning, they were concentrating so much on just the nodules on my body, they weren't paying attention to the fact that the itch was so relentless it was interfering with my day to day. So one of the things I did, and this is just an opinion I have, and I this could work for any ailment anyone's going through journal, what you're dealing with, because when you go into that doctor's office, you can very clearly say you don't have to try to remember, I'm getting older. I forget everything. So I write everything down. Try to remember what this made you feel like how the scribe, where's the itching concentrated? Where is it taking place? How will the nodules morphing? Were they scabby? At this time, as much information as you can compile, and I write it right in my little apple notes, anywhere you can write it, so that when you walk into that doctor's office, they have as much information as possible to help you deal with what you're dealing with. So that's something that I would say, in terms of how they can treat it, because if you give them all the information that they need, they can get your diagnosis quicker, then they can figure out how to treat it. So that's the biggest thing that I would I would probably say is a good idea for you to make sure you give me your sharing your information with the doctor, with your dermatologist.

Daricha 12:13:33

I totally agree. Another thing I would say, directed mostly to dermatologist, MDS, whoever you are, understand your patient. When you come in, I don't know if you notice, always pay attention when you go to the hospital, they'll come in, patient, name, date of birth. Don't just look at it as my clipboard. Come in, find out who am I? No, I am. Go to the nurse and ask the nurse, okay, what did she I want you to come in and have a conversation with me. Get to know me. At for me here, what I've been dealing with. Don't just like, lick it and read it. Okay? She said, itching. No, come and have a seat. Direction. What have you been experiencing? You know, open the room so I can talk to you. Because especially when we're diagnosed with something we don't know, sometimes we're a little bottled in and we don't want to express how we feel. We don't want to express how we feel. We don't want to express what we're dealing with. But physicians need to come in and understand your patient, not just for patient ID, come in and figure out, who am I, what am I dealing with? Actually have a conversation with me. Don't look at me as just a diagnosis that you want to diagnose. Figure out what's around my condition. I can say for dermatologist, you know, and,

Rose Sherrod 12:14:36

yeah, what we have, what's the the next question, were your family and friends supportive of your decisions to participate?

Daricha 12:14:46

Yeah? Oh, mama, well, my grandma, because, you know, she's

12:14:50

old school.

Daricha 12:14:54

Hold on now. And she is, I come from because I'm Haitian. That's my culture. Back. She was like, oh, like, she was like, she was not, she was like, walking it like physical. Say you're gonna let them kill you. I'm like, Oh, my God. So you know you it's just like, that's, I said, knowledge be teachable. The smartest person in the room is not always the smartest, okay, sometimes you have to allow room to learn different things. So I would be like, you know, goodbye. Like, relax, you know. But other than that, like my mom, very supportive my sister, they just wanted, just imagine, you know, they're literally at night, we're up to, like, four in the morning, itching. So my mom was for anything that can help anything, you know. And sometimes not everybody have that support system, and that goes back, yeah, just let your patients know that you're here for them whenever they need to, like, now they even have, like, um, my chart where you can physically, like, chat with your dermatologist, yeah, doctors, you know. So even if you don't hear from your patients, send them a message like, hey. How you're doing, you know? So I just think it's just that support, that encouragement everybody needs, sometimes. So, but yeah, I had, like, my family was very supportive. Yeah,

Tiwana 12:16:02

they were supportive after I made the decision, I didn't really involve me, to be very honest with you, but once I made the decision, it was nothing but support, and they would check

12:16:13

in. So that was good.

Rose Sherrod 12:16:15

Awesome, awesome. Wow. This has been very informative. I myself have learned a lot. I have learned a lot. Thank you both so much for your time, for everything, your energy, your stories, your lived experience, for sharing it with the community. It looks like we've answered all the questions. This has been a marvelous, marvelous time. Listen, if you're joining and you're not a part of the NOWINCLUDED community, I'll share the link to the community. You can join the community and get to know these beautiful ladies, all the people in the community that are there, and we, we're all here just to support each other, right, and learn from each other. So thank you again, so much. And listen, I'll see you all in the community. It's been a great one.

Tiwana 12:17:05

Thanks for having us. This has been amazing until next time.

Daricha 12:17:11

Okay, let me sow we're.