

Episode 2: Frankie's Story

Narrator 00:00

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Frankie Lee 00:13

I think that like having a support system when you have something like asthma or really any chronic illness it makes the world of a difference to feel like you've got people sort of backing you when you're going through it.

Sarah Shaw 00:26

Welcome to The Asthma Podcast, a podcast that shares the real stories of people living with asthma. I'm Sarah Shaw, Senior Manager of BIPOC Community Outreach at the Global Healthy Living Foundation. In this edition of the asthma podcast, we will dive into the stories of LGBTQ plus asthma patients within the theme of "Love Should Take Your Breath Away, Not Asthma," exploring how LGBTQ plus individuals navigate identities, relationships, and asthma all at the same time. By sharing these stories, we hope that you feel inspired, heard, and more empowered through you or your loved ones as asthma care journey. In today's episode, we'll hear from Frankie Lee, a trans asthma patient who enjoys streaming and works in tech support. Frankie talks to us about the importance of support, listening to your body, and the value of self-advocacy. Let's dive in.

Frankie Lee 01:24

My name is Frankie. I use he/him pronouns. I have asthma, and a little bit about me, I work in tech support. And I'm super into gaming and streaming and all those kinds of things.

Sarah Shaw 01:38

Wonderful. We're so happy to have you on the podcast here today. So let's jump right in. The podcast is about asthma. I wanted to talk to you a little bit about what your earliest experience or memory of asthma is. Can you tell us also about like what your experience has been thus far with your journey with asthma?

Frankie Lee 01:55

Yeah, absolutely. I think my asthma actually was at its worst when I was when I was really young, which I think is relatively common. Don't quote me on that. I feel like that's the experience I've heard from other people that I know with asthma. So I was in and out of doctors offices a lot as a kid just with like really severe allergies, and then asthma as well. And so I definitely remember, you know, being a kid in in my PE classes and always having my inhaler on me or having to sit out a little bit just because I couldn't quite keep up. But as I got older, and preventative inhalers became more prominent, I started using those and that made a huge difference for me. So that's really helped me kind of manage my asthma, sort of going into my adult life. But certainly as a kid, it was really rough. Just because there

were a lot of things that I couldn't quite do, or there were a lot of things that would trigger it definitely grateful for those preventative inhalers now.

Sarah Shaw 02:47

Do you mind talking to us a little bit about the things that your asthma kind of prevented you from doing from a young age? I'm sure that must have been really frustrating as a child.

Frankie Lee 02:55

I was definitely a more active kid. So I did like a lot of sports. I played soccer, and then softball, and it was definitely harder when I couldn't do like those longer distance things and just sort of being outdoors, like with grass, or pollen and stuff like that, that would sort of trigger my asthma as well. So those aren't really things that you can avoid. So there were certainly instances of just having to sort of sit out when it came to participating in sports or being in my gym class at school. Just little things that like the other kids were doing that I was sort of sitting on the sidelines to, for a little while so.

Sarah Shaw 03:33

It's funny, another person who were talking to mentioned PE classes being one of the first times that they realize that they were quote unquote, a little bit different from their other peers, that that was one of the stark differences. Were there other, I'm curious to know, were there other kids your age that were also experiencing similarities like asthma at that young age? Or were you kind of singled out?

Frankie Lee 03:57

Not that I knew of, to be honest, it's certainly possible, but there weren't any that I was aware of. I definitely remember it sort of feeling a little bit isolating when I was younger, just because especially taking into account sort of, I've always been like sort of a heavier kid. So even when I was younger, being active was a little bit more difficult for me and then adding the asthma on top of it, not that you can't be healthy and heavy at the same time. But for me, it was a difficult thing. And so that sort of there was the singling out because of that, and then there was the singling out because of the asthma. And I think those lines got kind of blurred when it came to teachers and stuff like that. So I think a lot of the time they actually didn't believe me and kind of felt like I just wanted to sort of sit on the sidelines. That wasn't that wasn't the case. Yeah, that was certainly how it felt at the time for me, you know, it was it was definitely one of those things. It was a little bit difficult, but I can look back at it now and sort of laugh but yeah, as a kid it was a little bit difficult.

Sarah Shaw 04:59

Yeah. especially when you see other kids running around playing, do the things that you want to do and then to have your PE teachers or your teachers, like look at you and be like you want to be doing this actually, no, my chronic illness is preventing me from doing said thing. That's unfair. And I'm glad that you're able to look back on it now, and, you know, to see what was going on, but I'm sure in the moment in those and it was it was difficult. Yeah. How is your asthma now, like now that you've, I want to say grown up, but now that you're older, how is your experience with asthma now?

Frankie Lee 05:35

Yeah, it's much better managed now. I feel like the preventative inhalers for me were sort of the start to kind of getting it under control. I was sort of surviving on rescue inhalers prior to that. So now I'm just sort of on my two puffs in the morning, two puffs at night, preventative inhaler. And then I really can't remember the last time I had an asthma attack, which is obviously, really nice. That's really great. Yeah, I know, that's not the case for everybody with asthma. So I'm really lucky that those inhalers have made a huge difference for me.

Sarah Shaw 06:07

I'm so glad that you have treatment, and that's helping you manage your asthma conditions. Not switching gears, but kind of going a little bit deeper. The theme of our campaign is called "Love Should Take Your Breath Away, Not Asthma," what does that mean to you? What is love in terms of friendships, companionship, relationships mean to you in terms of your asthma care?

Frankie Lee 06:30

I think it means everything I mean, especially with what we were just talking about being a kid and experiencing sort of just that extra added layer of sort of awkwardness, just navigating being a kid in school, and, and all of that. Having support and love when you come home from school from the day those are like, that's really key. My partner now also obviously, is fantastic, and has been super understanding and helpful with stuff like that. I think that like having a support system, when you have something like asthma, or really any chronic illness is huge. It makes the world of a difference to feel like you've got people sort of backing you when you're going through it and having a rough time. So yeah, I have it's everything for sure.

Sarah Shaw 07:18

Absolutely. And I think just having the support of not only the people that know what you're going through, but maybe the people that don't know what you're going through having that extra validation and being like I see you, I may not know exactly what you're experiencing, but I want to figure out how to help you. And that actually is going into my next question of I know, you mentioned your partner, how has asthma impacted your relationship? And how do you and your partner plan for attacks? Or how do you talk about asthma with them? Do you want to share with our listeners about how to you know, navigate that?

Frankie Lee 07:54

My partner also has chronic illness. And so that was something that I was aware of going into our relationship. And it was really like a point of understanding between us. It was something that we both sort of got in different ways. So it's never been an issue, I think the biggest thing that's been a struggle that I think some people might relate to is COVID, actually. With COVID, well, I should preface that my partner and I are long distance by like 3000 miles, or something close to that. And so during COVID and even now traveling for me was just sort of out of the question, it was, you know, with how much COVID affects your lungs, I just didn't feel like I could risk that it was too scary for me. And I still struggle with being afraid about that. And so the fact that my partner was so understanding about being hesitant about traveling, and being with people really made a big difference for me to not be anxious on top of being anxious. They were so understanding and we spent tons of time together on voice calls, playing games. I'm really, really grateful for that.

Sarah Shaw 09:04

I'm so glad that you have that supportive relationship and someone that it makes it a little bit easier when you're in a friendship with somebody or a relationship with somebody or companionship with somebody who already gets it and has a chronic illness. All I can say is I hope having these conversations, having people listened to these stories, I want that to become the standard for partnerships, for relationships, for friendships, just that having that added layer of empathy and patience and understanding because I feel like that can make a world of difference for somebody living with chronic illness.

Frankie Lee 09:35

100%. I feel like it's rare to find that. It can be really hard to find that. I know that's not the experience for everybody and it should be 100%.

Sarah Shaw 09:43

Absolutely. Thinking about you know, where we started this conversation where you're talking about how limited and what you were able to do as a child to now what you're able to do what have you gained back from a better asthma treatment?

Frankie Lee 09:57

That's a tough question for me actually. And I know that it probably isn't supposed to be. But it is. I think, like, there's a lot wrapped up in what I really wanted to do as a kid versus what I'm able to do now. And I don't know that I realized that until this moment. But I do think that sort of the experience of sort of not being able to do all of the things that all the other kids were doing, or at least not do it the same way that they were doing it definitely held a lot of weight for me. It was something that I really struggled with. And so I think that now that I'm older, I've sort of kept away from those things, just because they always felt out of the question. So maybe that's something I need to explore a little bit more, because I don't know that I ever did that, that ever really tried to re-explore that. But I will say being able to manage my asthma, it makes a world of a difference in terms of your mental health, like having struggles with breathing can be really exhausting. And I remember just sort of waking up certain nights as a kid and just being like, just not being able to breathe, and that doesn't happen anymore. And I think that kind of thing where I can sleep through the night, and not have an issue like that makes just such a huge difference for me emotionally. Being able to get a full night's sleep, and experience that I think is one of the biggest things. So yeah, I think that's what I would say right now. Definitely something to revisit and re explore for me.

Sarah Shaw 11:23

Well, first of all, I think one that's really scary to not be able to breathe in the middle of the night. And I'm glad that you've been able to reclaim that part of your life back, that you're on better treatments, that you've able to have your asthma under control, and that you're able to get a good night's sleep. Because I'll tell you, not having a good night's sleep, and you know, this like can disrupt everything from thinking to your mental to anxiety to depression, like there's all these things that can come in that can interrupt not having a good night's sleep. So I'm glad that you were able to get that back into your life. And I think it's Okay, that you're saying that, you know, you haven't really had a chance to go back and

do the things that you weren't able to do as a kid. Like I think that's what this journey is all about is sitting down and reflecting about, hey, maybe now you know, this is something that I am at a place where I can do that. And there's no timeline right of when you should or should not be doing something. I live with a few chronic illnesses, one of them being chronic migraine, and there are some things that I wouldn't want to go back and try and do just yet because I'm anxious about, you know, possibly triggering a migraine attack. But then there are other things that I have started to do again, where I'm like, wow, I haven't been able to do that in like seven years. And I was able to do it for like the first time now that I have, you know, certain things under control. And there's no timeline on that. So I think that that's completely up to up to your own roadmap of when and you know, it's all about pacing. I think that that's so important for us to remember.

Frankie Lee 12:54

Yeah, absolutely. You can't really force it. You got to just kind of listen to your body and listen to your yourself. Absolutely.

Sarah Shaw 13:02

Yeah. And you have to, like you said have like the also the support of your loved ones there to kind of, you know, like encourage you and guide you and be your cheerleaders so to speak.

Frankie Lee 13:13

Yeah, absolutely.

Sarah Shaw 13:14

Being a member of the LGBTQ community, how has the LGBTQ community supported you in your asthma journey? Or what communities have you found that have helped you in your journey?

Frankie Lee 13:27

That's a really good question. And I'll be totally honest, I guess in my adult life, I haven't really been part of a super close knit sort of community that I've shared that with. I mean, I just haven't been part of much of like a big LGBTQ community in general. Online, I think would be the closest to that. And a lot of the friends that I have now are from sort of queer online communities that I've been a part of, and they've been supportive of me throughout everything, whether it was transitioning, or asthma, or, you know, surgeries, anything. The queer community is definitely, at least a queer community that I've been a part of has been just fantastic. I mean, completely supportive always, you know, sending little gifts of support kind words, even just like coming to the streams that I do to talk about whatever we, you know, most of my community that I have in my stream is queer. And I just find that there's just a lot of empathy, and a lot of kindness and a lot of support. I think asking questions is really helpful. And that's been a constant in that and something that I've really appreciated. So just trying to gain understanding about something, and then actually actioning on that understanding is huge. So I guess I would say that asthma hasn't come up a ton in my queer experience, at least in terms of community, but when it has, it's never been an issue and it's always been support and if anything just trying to learn more about it.

Sarah Shaw 15:00

I think that that's the only way to do it. I feel like just having a community to support you is like the first big step when, regardless of where you're at in your life. I know that myself and my partner, we have a very, very small, like, not a huge, you know, queer community, but the community that we have, you know, it's sometimes it's a little. When I first started to try and talk to them about my chronic illness, I was so scared, I was like, Oh, my gosh, are they gonna judge me? Are they gonna, you know, and there was none of that, right? There was just this extra, I don't know, layer of empathy and understanding, I feel like because we're from queer communities that we already know, or at least for me, like what it's like to be discriminated against, and we so I feel like there's just this added extra umph of love that we able to give. So having these difficult conversations that would normally be really stressful and other situations are just a little bit easier, at least in my situation. I don't know if that's been the case for you.

Frankie Lee 15:59

100%. I think that experiencing any sort of like discrimination, in some ways, sort of allows you, and this is not me sensationalizing experiencing discrimination. People should never have to go through that. But I think that having to go through that adds some sort of layer of being able to understand people, put yourself in other people's shoes. That kind of empathy is really special, I think, and unique and being able to experience be on the receiving end of that, or the giving end of that is a really special experience. Because there's just like this level of judgment that is completely out the window, in my opinion, it's just sort of sort of taken away, and you don't have to worry about someone being like, "What the heck is that about?" There's just listening. Most of the time. Of course, there's a lot of, you know, intersections and layers to that. But I think the listening piece is really important.

Sarah Shaw 16:56

Absolutely. I 100% agree. In that same vein, I wanted to ask a little bit about you've mentioned transitioning. I want to know, like what you've been able to do in your journey, as an LGBTQ plus patient to talk to your provider about your gender identity. How can we make more doctor's offices more welcoming and more affirming for the LGBTQ plus community? I think that's an important thing that we that you might have insight on.

Frankie Lee 17:26

I think that's an awesome question, what I would say, just to give a little bit of context. First doctor I went to in regards to transitioning was when I didn't have health insurance. And so cost was a big piece of that, for me. I did a ton of research on sort of where to go, especially because I was nervous about the conversation. I was nervous about the reaction from the doctor, how I'd be treated. And so I actually found queer center up in Portland, where I lived at the time. And they had sort of like a small doctor's office, that was a part of their sort of what they did at that queer center. The doctor there was fantastic. He was super understanding, they just sort of got it. And because they were just part of the community. So they knew already, which was a really fantastic first experience, and something that I would definitely recommend to anyone who's sort of at those beginning stages of transitioning. It's really important to sort of have that affirmation. I know that's not accessible for everybody. But what I will say is that those queer centers, if they have something like that, accessibility was a really big thing for me at the time, because I didn't have health insurance. And they made a point to work with me. And I think most of the queer centers are really understanding about financial situations as well. So they're a good

starting point. That being said, that experience was a stark contrast between being with queer doctors. So going from that to doctors who weren't queer was really difficult. At the time, and this was only four years ago, but still, at the time, I think that it wasn't as common to even ask for a patient's pronouns. And so if they didn't really see you as who you felt you feel you are. They didn't. They didn't regard you that way. And they didn't ask. I think it's better now, when I got my surgery, even if it was a doctor who I wasn't working with, they would still ask and they would make a point to ask most of the time, but there were always those times, especially over the phone where, you know, there's the ma'am, it's just like by default, it comes out and it's uncomfortable. And I think that the doctors still aren't quite thinking that far ahead. I think that that the biggest thing when you're going to a doctor's office is that you shouldn't have to be going to a doctor who is trans or queer, to get affirmative care, and you shouldn't be having to go for something trans related to get affirmative care. I should be able to go to a doctor for asthma and still be asked what my pronouns are and then have the doctor use those pronouns. It's not that complicated to do that. And I don't think that happens often enough, especially from state to state, you're going to have a different experience. So I think it's so important to, for doctors to start thinking more about that. It wasn't an experience I had with any doctor that I went to, that wasn't for trans affirming care. I think advocating for yourself, while it's really difficult, is so important. Correcting them, when they misgender, you is so important. It's okay to not also. It takes a lot of energy to do that all the time. But if you can do it, do it. It's so important to advocate for yourself to have the care that you deserve, especially when you're going through any number of any kind of illness. I just think it's really important. It was really hard for me, but it made a difference.

Sarah Shaw 20:54

I like all of what you just said. But I especially like what you said about that. It's a process to advocate, it's not always easy. And I think that a lot of people maybe not inside the community think well, if you feel uncomfortable, speak up, sometimes it's not safe. Sometimes it's sometimes it's just really uncomfortable. Sometimes you're not at that level yet, with maybe it's the very first time that you're seeing this doctor, and you haven't established a relationship with them yet. There are many, many different variables of why maybe you don't advocate but I think being gentle with yourself and having grace. I remember the very first time a doctor actually apologized to me. I think we had done like five sessions together and on like the sixth session, she was like, "You know what, I have to apologize to you." And I was like, "Why?" She's like, "When I first met you, I didn't ask your pronouns. And I noticed on your intake form that you said that you were lesbian." And I was like, Yes, like that is you know, and I think just having that, you know, she had that reflection, and she had that grace, and she apologized. And like after it, I noticed that like after that, like a lot of my walls went down. So you have to have that level of trust and that level of grace and that level of understanding and a level of empathy on both sides where you're gonna make mistakes. And I think you have to get be in a level of like, you're saying to advocate for yourself. She never misgendered me, she never did any of that. But I didn't make it a point to say, "Oh, by the way, hey, here are my pronouns." Now, you know, I've been out for quite a few years now, I still get nervous bringing it up at the doctor's office thing, my pronouns are she/her, I'm in a queer relationship, I still get really, you know, I get anxious talking about it. But I think the more we see our doctors offices, you know, maybe writing on the intake. Having something as simple, as my OBGYN office, they have the rainbow flag, like printed on their little thing. And like, that is just like, okay, I'm in a safer space. And I can like, be myself. Just having little signals like that. I think just like little Bat Signals alerts to us to know that, hey, you're in a safe place. Maybe there's gonna be mistakes made. But if the

mistakes are made, it's okay for us to speak up a little bit about it saying, "Hey, by the way, you misgendered me," or, you know, "You're using my dead name," or your you know, something. Yeah. So I appreciate what you're saying. This has been such a great conversation so far. And I had just have one final question. And that's about advice. And what advice do you have for someone that maybe is just starting out on their asthma journey? Maybe they just got diagnosed or maybe they think they have asthma, but like, aren't sure what to do. What advice would you give to somebody starting out?

Frankie Lee 23:34

I think, and it's something that you just said, but I think it applies to this also, which is be gentle with yourself. You don't have to push yourself beyond what your body is telling you that you can do in that moment. I think that's the biggest thing is, certainly in my own experience, it's been easy to want to push myself past my body's limits, because that's what it seemed like everyone else was doing, or I felt like what was expected of me. You don't have to do that. I think the most important thing is to listen to your body, listen to what your body is telling you and do that. It's okay to just lay down for a while. It's okay to sit it out. It's okay to pass on stuff. If that's what your body needs. I think that's okay to do that. Just being gentle with yourself when you're not feeling well is so important. I think also finding community, finding support, finding people who can sort of be there for you. If it's something that you're sort of just starting out with, I think that's really, really important. Talking to people about it. Just sort of pushing yourself to talk about it is really going to help in the long run. Because you'll have people who understand what you're going through, or at least want to support you and be there for you through it. So I think that's really important. Also, there's a million things in terms of treatment that you could say. But everyone's so different. And so I think that the biggest thing that you can do if you're just starting out on your asthma journey is really start to explore it. If care is accessible to you, preventative inhalers are incredible and, and sort of researching that is really, really important. But I think the biggest thing that's ever gotten me through is having support, having community, and really listening to my body and what my body needed, so.

Sarah Shaw 25:17

Those are some really, really great pieces of advice. And I know if I were just starting out on my asthma journey, and I listened to this, it would make me feel a lot better knowing that one I'm not alone. I'm not the only one going through it and that there is a community out there that is there to support you and get you through. So thank you, Frankie for being a part of this community. Thank you for coming on podcast and sharing your journey, your expertise, your experience and your advice with us. It's been a pleasure.

Frankie Lee 25:45

Absolutely. Thank you for having me.

Sarah Shaw 25:47

Thanks for listening to this special episode of The Asthma Podcast, where you hear about the stories of LGBTQ plus asthma patients. We touch on navigating love, relationships, and their health. If you liked this episode, please give it an honest five star rating and subscribe. Once again. I'm Sarah Shaw, and I will see you next time. This episode of The Asthma Podcast was made possible with support from Amgen and AstraZeneca, sponsors of the Global Healthy Living Foundation.

Narrator 26:23

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