Scanxiety: Managing Drug Resistance Fears with Jaymie Knox

Jaymie Knox (00:00):

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Intro Voiceover (00:09):

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James Hiter (00:25):

Hi, I'm James Hiter and I'm living with lung cancer and welcome to Lung Cancer Foundation of America's podcast that we call Ask Me Anything. Today we're going to be talking about drug resistance. Specifically, people have targeted drug therapies that some cases can last for a long, long time, in many cases, years. But eventually, many of us have to face the reality of these drugs becoming ineffective or our cancer kind of starting to outsmart them. So joining me today to talk about that and the mental gymnastics that goes along with that is my great friend, Jaymie Knox.

Jaymie Knox (01:04):

Hey.

James Hiter (01:05):

And Jaymie's living with ALK-positive lung cancer with lots of great treatment options out there for you, but not all of them last forever. So Jamie, let me just ask you right out of the gate, how are you thinking about your treatment and how are you gearing up for the potential that someday it might stop working?

Jaymie Knox (01:29):

It's never going to stop working. No. I would say from when I first got diagnosed to where I am today, I feel a lot better. And that's because when I was first diagnosed in December of 2018, I was on alectinib. I'm still on it now. But at the time, that was the latest and greatest. My doctor made it a big deal. We're putting you on the latest medication, alectinib. It's great for treating ALK-positive lung cancer. It's going to give you your life back. You're going to feel like nothing is wrong with you and it's really going to be night and day and it's going to be a game changer. And so that was all very exciting and very refreshing, but it was the only. And so most of the time while I was on this medication in the early days, I was constantly living with this fear that if anything happens with progression or if I got a trache cancer and it's smart and it gets past this medication quickly before science has had a chance to make another one, I don't know what my next step is going to be.

(02:23):

And so that was always very scary and it's always a thought that was in the back of my mind. But as I've become more of an OG in the lung cancer community, if you will, a veteran, if you will, once you hit past that five years, you get to wear that little name talk there. But now that I've been on this medication for a long period of time, science has now come up with quite a few more to treat ALK-positive lung cancer and some other really exciting treatments and concepts and ideas and theories that are on the cutting room floor. But there's other options now. And so that nervousness and that scaredness has kind of gone away a little bit because I know that I have another ... I can leapfrog to the next ... Oops, sorry. Leapfrog to the next treatment, if at all possible.

(03:11):

And I know that with the next medication is going to come new side effects, is going to come new issues and ways of life. And you don't really know how long you're going to last on that medication, but just knowing that there is something else makes me feel a lot better. And adding to that, my care team has always been great and communicating with me like, "What's going to happen if something happens with progression for me? What's my next plan or what's plan B?" And so I'm very firm in knowing that my doctor has a plan B and we're good to go, even though I don't agree with it, but there is a plan B and it's nice to know that that's there. Should anything happen, it takes some of the burden off of thinking like, "What if? " That what if question is not really there anymore.

James Hiter (03:51):

Sure. I mean, you've done what we all were told, at least I was told when I was first diagnosed, that you have to live long enough for them to come up with more solutions.

Jaymie Knox (04:00):

Yes.

James Hiter (04:00):

And so it sounds like at the time of your diagnosis, there was one solution and now there are more than one solution for your specific type of lung cancer. And so by the way, we call that drug resistance when our bodies are a cancer in our bodies decides that it can outsmart it. And so one of the things that I know you feel strongly about as well is that we've heard people say that the patient failed or that this person ... And so maybe speak to that because I know you share the same ideas.

Jaymie Knox (04:27):

Yeah. So it's like using that patient's first language. It's not the patient failing, it's the medication failing the patient. It wasn't something that we did as if we're out there physically battling. It's something that the medication failed to do. So I like the idea of talking with that patient centered sort of lingo because it just takes the, not stigma. I don't know what the word is, but it takes that sting away from saying, "Oh, I failed this medication." No, the medication failed me. It takes the burden off of us as the patient.

James Hiter (05:00):

Yeah. So these medicines really, what they do for us is to buy us more time. And we've talked about that. I sometimes call it my renewed lease on life when I get a good scan. My four month lease on life just got renewed. I

Jaymie Knox (05:13):

Like that.

James Hiter (05:14):

I'm taking

Jaymie Knox (05:14):

That.

James Hiter (05:18):

There's a lot of uncertainty though that comes with living with a targeted therapy that is working. How do you manage that uncertainty?

Jaymie Knox (05:29):

So in terms of uncertainty, the fact that I've been on this medication for so long is the only uncertainty that I deal with because the average time that people are on my medication is like two years and I'm looking at year seven. So I'm way past that curve at this point into unknown territory. And so for me, that uncertainty is very scary because I feel like every scan I go into when I first got my diagnosis and I was on the medication and it was working and everything was shrinking and we're good, the fear wasn't really there because it was working or it started to subside. Now that I'm seven years into the game and I'm seven years into this medication, every scan gets to be a little bit more scary than the next because I'm just waiting for that shoe to drop, waiting for my body to say, "All right, we've let this medication run its course long enough.

(06:18):

It's time to try something different." So I think I more or less, like I've said before, your scan is going to be what your scan's going to be. I have to just be confident in my care team knowing that they've got my back and I have a plan B and just continue to hope that I have a great reaction to this medication. So right now, like I said, year seven and my next scan is coming up in, what, June? So now that we've moved to four months, it's harder to keep track. It messes up my month's calendars.

James Hiter (06:49):

Yes.

Jaymie Knox (06:49):

Yeah.

James Hiter (06:50):

Yeah. So do you remember when you first became aware of the idea that this medicine may sometimes stop working?

Jaymie Knox (06:58):

Yeah. Well, first day they prescribed it to me. Okay.

James Hiter (07:00):

So they talked about that right

Jaymie Knox (07:02):

Out of the gate. Right. Right out the gate. My oncologist told me, "Your prognosis is that you're going to be on this medication until your body develops a tolerance to it and you have progression." And then he was like, "Hopefully there'll be another medication on the market that we can move you to and we'll continue down the path like that. " So I mean, right from day one when I got this medication, I was aware that it could fail at any time, which also added to my nervousness.

James Hiter (07:23):

Yeah, of course. And so now that you have, you know there are other options out there, is it part of your doctor and your conversation in a regular appointment to talk about what would be the next step?

Jaymie Knox (07:36):

Yeah, occasionally. We've got a plan B in place. And so with that plan B, we haven't really strayed from it. It's still the same plan that we've had from sort of like since I started treating him about a year and a half ago. I think as new medications come on board, that conversation may adjust and change with the times. But right now, I think the next jump for me has been established for like what's next after ALK positive or for ALK positive when alectinib fails. There hasn't been anything new since then in terms of what the next trajectory is. So we're pretty set on plan B, so it hasn't been a regular conversation, but I know that he's keeping his ear to like what's current in the lung cancer sort of industry and I'm sort of keeping my finger to the pulse too to like for the newest, latest and greatest, like the vaccines coming up and all that kind of stuff.

(08:23):

So I'm trying to keep my eyes and ears out for new things and so is he. So as we progress, we'll change our plan, but right now plan B is still the same plan B.

James Hiter (08:33):

Yeah. Oh, that's awesome. It's great to have a plan B, and I just want to take a second and acknowledge that for some people diagnosed with lung cancer, the only thing that they have for as far as targeted therapy is there is no targeted therapy.

(08:48):

They have to do with traditional chemo and now some immunotherapy drugs that are available. And so I want to speak to that because that was actually for me and my brand of lung cancer was that there was no targeted therapy. So it's a lot the same anxiety though, because you don't have a targeted therapy doesn't mean you're still not trying to treat the disease and that there's still this fear of progression and that really is at the root of what we're talking about. So in your particular situation, there are targeted therapies that have some really pretty decent options available to you, but I also want to acknowledge that that's not necessarily the case for everybody, but for everybody, we still share the same kind of anxiety around progression fear.

Jaymie Knox (09:33):

Yeah, absolutely. And I absolutely sit here and know that I'm blessed that I've been on this medication. It's the latest and greatest medication and I've had such a wonderful response to it. My story's not going to be the same as everybody's and everyone's going to be just a little bit different. So I try to take my blessings and bring them forward to other folks, whether it be through education or impact or what have you, but I'm grateful that alectinib has worked for me as long as it has, and I pray it continues to work for me as long as possible. But yeah, definitely recognize that not everyone's going to have that opportunity. And if you are lucky enough to have a great response on your medication, it's a blessing for sure. So enjoy it and just count those blessings as they come in. And I also sit here acutely aware that my story can change at any time.

(10:20):

Tomorrow, I could have a shortness of breath and a cough and this whole rigamarole will start again. And so that's why it adds a little bit more flavor to my days because every day that I get up and I'm okay is a good day because I know at any other time I could be some of these stories that you hear out there with catastrophic progression and things like that. And so that's always in the back of my mind and I'm always very humble and just grateful that this is the journey that I'm on and the path that I'm on right now, totally understanding that at any time that path can change.

James Hiter (10:49):

Absolutely. Well, that plays right into my next question for you, which is, how is that anxiety about scans, so we call it scanxiety. It's really fear of progression that happens to be identified in most cases through a scan. How has that anxiety for you evolved over time now that you've had seven years of these scans going?

Jaymie Knox (11:12):

I mean, it still happens. It's always going to happen on some level. It was much higher in the beginning, like I said, because there was no medication for me to jump to. Now that scanxiety has morphed into when is that shoe going to drop with the tolerance for this medication in my body. And so that's what my scanxiety is more afraid of is like the progression based on the medicine failing me. So I think when it comes to reaction wise, how do I deal with it? Your scans are going to be what your scans are going to be. I say that, I say it until I'm blue in the face, but my anxiety for my scans or my nervousness about my scans is not going to change the outcome. You just have to know that you have a good care system in place, you have good doctors and a good support system so that whatever your scans come up with, you know that you have the people, the support and the resources you need to face it.

James Hiter (12:00):

Yeah. I think for me too, that evolution has been one of, there was a time when I thought progression was going to mean like a fast trip, a fast long walk off a very short pier. That's how I was kind of thinking of it. It's like, "Oh my gosh, if we have progression, then it's going to ... " And now I've come to understand over my span of time getting these scans is that, yeah, there's still more choices, there's still more options and you may eventually come to the spot where there are no more options, but for most people, there are a lot of options still out there. Every week on the Living With Lung Cancer Ask Me Anything podcast, we explore the questions that matter most to people living with lung cancer. We talk about new treatments, everyday challenges, breakthroughs in research, and the stories of patients and caregivers finding strength and hope.

(12:58):

If you want these insights delivered straight to you, subscribe on any podcast platform or go to lcfamerica.org. And if you know someone who could benefit from understanding and encouragement, share the show with them and don't forget to subscribe. Now, let's get back to our conversation. When you're coming up on a scan, let's say in the days or weeks leading up, and I know you have probably one of the best attitudes I've ever heard about what the scan's going to be, what the scan's going to be, but what goes through your mind or what are you thinking about in those days and weeks leading up to a scan?

Jaymie Knox (13:34):

Not weeks, just days. I don't give cancer that much control over my life. I refuse. I'll give you a day or two before the scan and maybe a day or two after and then you got to get moving. I got stuff to do. So I don't allow it to take over my mind like that. In fact, I try to forget that I have scans until I get that little calendar reminder on Google that's like, "Scans this week." And I'm like, "Ah, shoot,

(13:57):

Okay." I try to, as much as I can, forget when that appointment is until it's about a week out, so that I'm not constantly biting my nails and thinking about it all the time. But in the days leading up to my scans, I'm taking inventory. I'm thinking about, "Hey, you had a couple extra headaches this month. What's that about? " Or like, "Hey, you did get a little winded doing this and you didn't have any reason to be. " I start taking inventory of how my body's been reacting to certain things and what's been different, if anything, from my normal baseline. And if there is something that's different, I'm trying to avoid going down the rabbit hole or spiraling into thoughts of, "Oh my gosh, oh my gosh." But also understanding that progression can mean a small tumor somewhere else where they can treat it with chemotherapy and you continue on your same medication or understanding that a progression just because I have it doesn't necessarily mean I'm leaving this medication.

(14:58):

I might just need to add something to it or what have you. And so it's like rationalizing that anxiety a little bit like, "Hey, if it is something, you're probably still going to stay on your medication and they'll just zap it or something."

(15:12):

So sometimes you just have to lie to yourself a little bit, but rationalize it. And some

James Hiter (15:17):

If that is true. There are definitely things that you would just stay on the medicine and add in a SBRT or a targeted radiation therapy or something like that to take care of something else. Do you have a specific routine or anything that helps to alleviate some of that anxiety other than just waiting for the calendar alarm to go off?

Jaymie Knox (15:43):

You know what? I don't. I don't have any specific routine. I used to go to my scans by myself and I'd blast gangster rap, just trying to pump myself up a little bit and whatnot, but now I go with my husband and so there's no gangster rap, but we just kind of chat, you know what I mean? I think he tries his best to take my mind off it. But like we talked about before, there's only so much your significant other can do and there's only so much they can put themselves in your shoes, like conversation, cool, but I'm still in the back of my mind thinking about it. Even if you say don't worry, or even if you say it's going to be fine, I'm like, "That's cool. It's still happening

James Hiter (16:21):

Right here." There was a time early on for me where I wouldn't have dreamed of going to my scan without my wife with me for fear of getting bad news. And I think we've evolved now to the point where we're like, okay, even if it is bad news, and so now I do go solo to some of my scans, not all of them, but- It's

Jaymie Knox (16:41):

Not a bad thing. I think when I was going solo, I had more of a routine. I would think about certain things and obviously say a couple little prayers, but mostly I would just put on my favorite music and blast that and really get in the zone. And then when I got out of the scans, I'd go get what I wanted to eat. Now I got to consider other people in the car.

Jaymie Knox (17:00):

I'd be like, all right, you know what? And while I'm in my scans, because I'm claustrophobic too, which adds another level of scanxiety to me, and it's only for the MRIs. The CT's not so bad because it's a donut. But yeah, when I'm thinking about an MRI or a PET scan, which that's another podcast for another day, I had a whole panic attack and a PET scan machine and that was fun. But when I'm in the machine and I'm trying to quiet my brain's thoughts, I'm literally just thinking about food. What

James Hiter (17:29):

A great cooking mechanism.

Jaymie Knox (17:30):

I'm literally like, "Oh, you know what will be great right now? I'm going to go get some ... I want some tacos. Oh yeah, tacos sound great." No, you know what? Cold stone. I'm literally just thinking whatever my brain goes to in terms of food, I go down the rabbit hole with it and I just try to distract myself with food. And then whatever that food that got me through the scan is usually what I'll go find when I get out of it as a treat. But I mean, it's just the way to quiet your brain and it's a way to cope with the fact that I'm claustrophobic and trying to live through the scan and not have a panic attack, but then also it's just my little routine for myself. Try to take some of the bad out of it by making it good at the end and reclaiming some of that power back.

James Hiter (18:08):

Sure. I know this is also one that's interesting to talk to people. Do you share with your friends or on social media that you have a scan coming up or do you just announce it after the fact?

Jaymie Knox (18:22):

Yes and no. So I have a family group chat where I'll text them and be like, "Hey guys, prayers up. I got scans." And I just stopped texting them. I don't know why. There was no reason. I just was like ... And not that they don't care, but I'm like ... I appreciate the prayers, but honestly, I'm like, I don't want people waiting on pins and needles for me to get back to them to tell them my news, especially because now it's not like when I was treating at NYU, I would get results the same day. So that was like, I would go have scans and then maybe an hour or two later I would sit with the oncologist and go over it. Now it's like maybe I can get them on MyChart. My chart, they'll pop in before the doctor sees them and I'm like, "I'm going to look at them.

(19:04):

I'm going to look at them anyway." And then I have a thousand questions as to what they mean.

Jaymie Knox (19:09):

I mean, I don't want everybody on pins and needles waiting for me to give them the news. And if it's not good news, I don't want to have to tell everybody that, "Hey, just so you know. " So I'm hit or miss with it. Every now and then I'll tell, but most of the time I'm like, if I'm feeling particularly nervous for a scan, I'll put it out there and just say, "Hey, prayer's up." But mostly people are like, "You have scans coming sometime soon?" And I'm like, "I do. They're like next week." So I don't know, it's just kind of my own little ... Saving people the aggravation that I have to deal with of waiting for my results. You don't want your whole family waiting for your results too.

James Hiter (19:43):

Sure. No, the worst is when you tell people you have scans and then you forget that you told them you're going to have scans- And you

Jaymie Knox (19:49):

Never get back to

James Hiter (19:49):

Them. And you don't get back with them. And they are then worried that you got bad news. And afraid

Jaymie Knox (19:54):

To ask you.

James Hiter (19:54):

Exactly. Do

Jaymie Knox (19:56):

I ask if they're okay?

James Hiter (19:57):

I literally am like brainstorming my wife. Okay, who did we tell I was going to have scans because I need to call them and tell them that everything's good. You have a spreadsheet for that? Yeah, no spreadsheet for that. I should actually. I'm going to start making a list on my phone. So when you think about somebody who might be going for scans and maybe they haven't had a run of great scans that gives them that little bit of edge of confidence that I think you and I have evolved over time with a span of decent scans. We've both had bad scans, so we know what that feels like. What would you suggest to them as far as how to manage it, get through it, ways to kind of take the edge off of that?

Jaymie Knox (20:38):

Bad scans are hard to deal with no matter what. It's never good to see, oh, you may have something lit up that wasn't supposed to light up on your scan. It's never a good feeling because you're immediately like, you just go to the worst possible case scenario. I, in those kinds of situations, we just kind of let folks know like, "Hey, even if your scans light up, it doesn't mean it's cancer. It doesn't mean it's progression." A lot of things light up on scans that are not that. You could be fighting a cold, an infection, all kinds of things that would actually show up and light up as something to be worried about on a scan and it could just be nothing. So I would just say, like I always say, your scans are going to be what your scans are going to be. If you haven't had good scans traditionally very often, just prepare yourself mentally for that and know you made it through the last scan that wasn't great.

(21:28):

You made it through the last scan before that, that wasn't great. You're still here. If this scan is not great, so far you've got 100% history, like you're doing great, don't ruin your streak. But I would just continue to try to pour love into them and let them know like, "Hey, whatever the outcome is, you've got the team around you, the resources that you need, you've made it through all the rest of them, you're going to make it through this one too."

James Hiter (21:51):

You mentioned earlier having a plan B, I think also going ahead and having that conversation. And my doctor and I have had that conversation and the plan B has evolved because the medicine has evolved, but knowing what ... Okay, so if I have a bad scan, what are you thinking? That can sometimes take a little bit of that edge off too if you're more of a pragmatic, like what am I going to do next kind of person to know that there is a plan B, even if that plan B isn't ideal, maybe that treatment has a lot of side effects. Because

Jaymie Knox (22:25):

I mean, a lot of cancer and the scariness behind cancer is the unknown, the not knowing part. And there's so much gray area in the cancer world and in the lung cancer world in particular where we just have no idea. You don't know when it's going to happen, what's going to happen, what's going to come out, what's not going to come out. Anytime you can get a little bit of a plan is going to make you feel better. Grab onto that. Any semblance of a, "Hey, here's a plan B," hold onto that because it's just a little bit of an anchor so that your boat doesn't feel like it's just flying around in the storm. Plan Bs and different alternatives make you feel more grounded and more secure. When you don't have plan Bs or any kind of additional plans or anything to look at or to jump to if something happens, you kind of feel like you're just a drift and you're going whichever way the world takes you.

(23:17):

When you got a plan, it's like drop an anchor down like, "Hey, I know if I sway too far to the left or to the right, I'm still going to come back to center." So that's what usually I tell people, get that plan B, whatever it may be so that you can have that center point you can always come back to if you feel like you're straying too far.

James Hiter (23:34):

All right. Well, Jamie, I just want to say thanks for sharing your wisdom, seven years of wisdom now, all the ups and downs that come with that. It's been awesome sharing some time with you and I appreciate you sharing with our audience about your experiences. If you have interest in more videos like this one or podcasts or other information, I really encourage you, if you've been diagnosed or you're a care provider, become a student of the disease and that can manifest itself in a lot of different ways, but learning whatever it is that you can learn will really prove helpful. One of the best places you can learn more about lung cancer is at Lung Cancer Foundation of America’s website at lcfamerica.org. Thanks again and I hope you have a great day.

(24:18):

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