Diagnosed at 39: Living with ALK-Positive Lung Cancer 9 Years Later Transcript

Brandi Bryant (00:00):

I'm getting to enjoy all these moments and make beautiful memories with my children and with my friends and other family that I would not have been able to do if it weren't for those people in the labs and other advocates.

James Hiter (00:16):

Living With Lung Cancer: Ask Me Anything. Real conversations with people living with lung cancer. Learn from their personal journeys and expert insights. Subscribe now and never miss an episode. Welcome to Living with Lung Cancer: Ask Me Anything. I'm James and I'm living with lung cancer. Today we're talking about ALK-positive non-small cell lung cancer. The advances in treating this disease are astounding. Many survivors are able to keep it under control for years. My friend and fellow Speakers Bureau member, Brandi Bryant, is living proof. She was diagnosed nearly 10 years ago. Brandy, let's start with your diagnosis. Tell us a little bit about that.

Brandi Bryant (01:01):

So in 2018, I had... Well, at the end of 2017, I had gone to the doctor because I was experiencing some shortness of breath and I thought at the time I was 39 years old, I'm like, "Oh, maybe I'm getting adult onset asthma or maybe it's allergies because I like to take walks." And I was experiencing shortness of breath whenever I'd come home from the walks and would try to talk on the phone. So I saw my PCP, and he ran some tests. He had me go get an x-ray, which showed something, but they thought it was pneumonia. So like many stories of other survivors we know, I was prescribed antibiotics, nothing changed. And then I was eventually referred to a pulmonologist and after a few weeks I was diagnosed with lung cancer, non-small cell lung cancer at the age of 39.

James Hiter (01:54):

Wow. So you had this x-ray. How long before you knew it was lung cancer and then how long before you knew it was ALK positive lung cancer?

Brandi Bryant (02:05):

So I was very fortunate to be able to have access to a pulmonologist and an oncologist in my community. I was actually walking to my pulmonology appointments originally, but the process took about two months. It was two months before I, because it was over kind of a holiday break. So it was about two months before I had the diagnosis from the time I initially saw my doctor and then another three weeks after knowing that it was lung cancer, that it had a specific biomarker and that biomarker was ALK positive.

James Hiter (02:42):

So when the doctor broke the news to you, and then shared with me a little bit about what that conversation with him or her sounded like with the diagnosis, but also the ALK positive diagnosis.

Brandi Bryant (02:55):

I didn't understand what they were telling me because of course it's a complete shock that what do you mean I have lung cancer. And they told me at the time that they had sent my tumor off for testing. Again, this was a new world for me. I did not know what that meant. I didn't understand what they were saying when they were sending it for biomarker testing. I knew it would affect my treatment, but I didn't understand the details of that. So I didn't know I had extra hope at the time of the diagnosis. It wasn't until after I had been told I was ALK positive and because it took a few weeks after I had been diagnosed to get that biomarker identification, I had done some research. So I knew then that it was a good thing that I had that biomarker for my treatment options.

James Hiter (03:46):

Right. Yeah. I mean, what a game changer compared to those of us who have gotten a diagnosis of lung cancer, but not with such a targetable mutation.

Brandi Bryant (03:57):

Yeah.

James Hiter (03:58):

So there's been a shift in the lung cancer community of, we talk about a terminal disease. Now we tend to talk more about chronic or chronic illness. Now, it doesn't really change anything fundamentally about the seriousness of our diagnoses, but it does change the conversation a little bit when you think about treating this as a chronic illness. So what does it feel like to live long-term with lung cancer?

Brandi Bryant (04:25):

It really changes the way that I choose to interact with my providers because there are side effects. We know that there are tons of side effects. Yes, I'm doing well. The cancer is not detectable in scans. However, there are many, many things that I won't go into details with that go on that I have to coordinate with a care team. I have a rheumatologist, I have an ophthalmologist, I've got all of these other ologists now. I've got an oncocardiologist. There are so many other things that we have to consider. It's like, okay, yes, you were diagnosed. Yes, I'm very blessed and thankful that my medication is working, but now that it's been almost nine years that I'm on this targeted therapy, what does that mean for all of these other things that are happening in my life, the rest of regular life? How are we going to measure that?

(05:24):

So it's important to have a team that communicates with each other.

James Hiter (05:28):

Yeah. I mean, kudos to you for having that team. And I don't know how much of that is, I know for some of that kind of stuff is dumb luck and some of it's because we worked our butts off to build the team, but especially the oncologist cardiologist, which is something that we're hearing more and more about, very common in breast cancer, less common with lung cancer, but yet something that we have.

Brandi Bryant (05:49):

And it was because of other survivors who've had heart issues. And even part of my initial diagnosis when I was initially diagnosed at stage 3B, I had a large pericardial effusion that was malignant that bumped me to stage four and allowed me to get on targeted therapy. That's the fluids they tested to... Well, no, it was my tumor sample, but that gave me the ability to qualify for that medication. And I had a cardiologist and it was important for me when I'm talking to my other friends and survivors to still remind them, that's part of my own advocacy. Guys, I need to make sure that we're checking on my heart because I've had 30 rounds of radiation and I'm a woman and I want to make sure that I'm okay, but is there anything that we need to look at? So that's advocacy on my part.

(06:46):

You'd still have to build the team. There's a team that you come with, but then you have to keep reminding them that, hey, don't forget.

James Hiter (06:54):

Yeah. The younger you are, the longer you potentially are going to live with this disease just by diagnosing your 30s. If you can live to a ripe old age on average, that's a long time to deal with all of the potential side effects and the things that can go wrong.

Brandi Bryant (07:14):

So even one side note is that because I was diagnosed at 39, I hadn't even had a mammogram yet. And because I was getting all of these scans, I'm thinking like, "Oh, do I need a mammogram? I still need a mammogram." And it was something that completely slipped through my oncology team's hands. It was my primary care physician who reminded me, "Yeah, you still need to get this." And then when I followed up with my oncology team, they're like, "Oh yeah." So it's so many things. It's really a lot on the patient to have to remind their team and have a checklist as we are living longer and longer with the disease to make sure that we're staying on top of our health.

James Hiter (08:04):

Yeah, it's funny. So one of the things that I always try to look at is what's the silver lining, right? So when I was diagnosed at 46, I'm like, okay, silver lining. I'm going to not outlive my parents. Okay, maybe not a silver lining, but at least you know what I'm saying? I don't have to deal with that part of life. I am not going to ever have to have a colonoscopy. That's going to be great. Well, then you live long enough and then all of a sudden now my parents are getting older and you have to start doing these other screenings and things because now there's a chance we're going to live long enough to need some of those other screenings.

Brandi Bryant (08:37):

Yes, exactly.

James Hiter (08:39):

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today and don't forget to subscribe. Now, back to our conversation. I mean, one of the things that I know everybody worries about, everybody that's on any kind of therapy or like myself, just kind of in a holding pattern, you worry about progression, you worry about what happens when the cancer outsmarts the drug and off we go. Tell me a little bit about the worry that you have about the potential that your targeted therapy stops being effective for you.

Brandi Bryant (09:38):

I mean, it was a constant fear, especially because when I was diagnosed, I'm a mom of four. My youngest child was three years old at the time of my diagnosis, so I just wanted to live long enough for him to remember me. And then once it looks like, oh, I think I'm going to do okay, it takes a lot to not worry. It took me years to finally get to a point where I was like, okay, this is what it is. It's because I got therapy, there's therapy, and then I made a plan. I'm just like, if this is what happens, this is where we are. I stay on top of research and that gives me hope. Staying involved in the community of other survivors and knowing that there are other options available helps me not to have as much anxiety about progression.

James Hiter (10:35):

Is it something that you and your doctor discuss at your regular meetings or is it something that you just know that if it happens, you'll figure out a plan then?

Brandi Bryant (10:44):

We haven't discussed it in years. I think I know for sure if I brought it up to her, we would talk through the options and maybe I'll talk to her about it when I see her next month just because it's a good reminder that, okay, even though you've had good scans, let's talk about the what if, because there's new what ifs now,

James Hiter (11:04):

Right? Absolutely.

Brandi Bryant (11:05):

So what would be a good option for me? It's good to know. It's good to just have a plan because you're right, James, my plan has changed actually.

James Hiter (11:14):

Yeah. Well, the plan B for a lot of us has evolved over time. I was pestering my oncologist all the time and my wife too, because she's the planner and the worrier. So what are we going to do? What if the next scan's bad? What do we do? I'm glad we had a good scan this time. What if the next one's not good? What do we do? And so we would play that game, but also recognizing that over time the options evolve, and that's especially true with ALK-positive lung cancer.

Brandi Bryant (11:42):

Yes. ALK-positive, I am very fortunate to have that biomarker. I'm extremely fortunate to have been on the same targeted therapy for eight years. I started my primary treatment was chemotherapy and radiation, and then I have been on targeted therapies since that progression to stage four. And I have many friends who have not been able to, even ALK-positive friends who've not been able to stay on the

same treatment. But ALK-positive keeps coming out with more. There's more drugs than I even still have in my mind. It's like, okay, I used to know this is the next one, this is the next one. There are four next ones right now.

James Hiter (12:28):

It's fantastic.

Brandi Bryant (12:28):

It's amazing the research that is being done.

James Hiter (12:32):

No, that's awesome. And I think having options is such an anxiety reducer for those of us that have been diagnosed.

Brandi Bryant (12:44):

Yes, yes, it does. It gives me more hope. I mean, hope is what we all hold onto.

James Hiter (12:51):

Right. Now, one of the things that we all have concerns about, but seems to be especially prevalent in the ALK-positive space is brain metastases or brain mets. Can you share with us a little bit about how you deal with the mental side of having that concern or wondering about brain metastases?

Brandi Bryant (13:12):

Yes, I actually have a story about that. So in 2020 when we were all locked down, I was sick with something, not COVID, but something very bad that made it hard for me to take my medication. Fast-forward to 2021 when I could finally go see my physician, and I had brain mets. They saw brain mets. They were small. It was like two or three brain mets, and I was completely panicking. This was only three years after. I still was in the what if, what if, what if, what if? So knowing that there were options of radiation, possibly increasing the dose of my medication, and finding an expert also. So I have a general thoracic oncologist, but seeing somebody who focuses on ALK positive really gave me relief. So I went to see them because they knew I hadn't been able to take my medication as well as I should have been.

(14:16):

I was just told to suck it up and just take the medicine. And thankfully I was able to, when I got my scans again in six weeks, the brain mets were gone and they have not been back there since then. But now I know I have this plan because of the very precise radiation. I've had friends who've had surgery and increased medication changing to another dose. So it's like, again, the brain mets are

James Hiter (14:47):

Terrifying,

Brandi Bryant (14:48):

But I've also have friends who have stable brain mets. It's one tiny met and then nothing's happening. So it's good to know that there are so many options even with the fear of brain mets. Brain mets still

doesn't mean that you're not going to be here for a long time. It doesn't mean that there is no hope. It doesn't mean that you'll even feel a difference in your life. So I try not to worry too hard about what could be with the brain mets because I know that there's a solution.

James Hiter (15:21):

Absolutely. No, that's great. Brandy, finding your voice after a diagnosis is really important, as we've talked about already. What advice would you have for patients who are trying to find their kind of self-advocacy voice after a diagnosis?

Brandi Bryant (15:39):

I would definitely, for me, I was taken under the wing of other advocates and I just followed the lead of other advocates. I think it's good to see what they're doing and move in at whatever pace you're comfortable with, do a small level of volunteering, learn how to tell your story, just whatever you're comfortable with. But it's really been helpful for me to have other advocates who've taken me under their wing and just shown me what they're doing, then I'm following in their footsteps.

James Hiter (16:14):

Well, I think the community's very lucky to have you as one of its spokespeople. And when the other side of advocacy is kind of that clinical self-advocacy, trying to make sure you have the cardio oncologist person in your team, what suggestions would you have for people regarding making sure you're speaking up for yourself as best you can?

Brandi Bryant (16:41):

I always say don't be afraid of the doctor. This is supposed to be someone who's your partner, someone who is on your care team. They call it a care team because it needs to be someone who cares about your health. And if you have someone who you don't feel like is listening to you, find another provider. I mean, as best as you can, try to find another provider or at least try and get a virtual second opinion or just something to give you comfort in knowing that you are being listened to. And it doesn't even just have to be one part of the team. If you have one or two people on your team, part of your care team who are really caring, then that can help you learn how to talk to the others who you might struggle with.

James Hiter (17:30):

Yeah, people who are regular listeners to the podcast know that I say often that it's important to become a student of the disease, and that looks different for everybody, but for no matter who you are or how intellectual you think you are or whatever, it's just diving into the disease itself, learning as much as you can so that when your care team is talking to you, you can understand more of what they're saying. And when you don't, you can speak up and say, "Hey, I need you to explain that again, but maybe in a way I would understand it."

Brandi Bryant (18:06):

Yes. Yeah, I agree completely that it's important that you feel comfortable with whatever your care team is giving you for your treatment plan and to always speak up and don't feel like you're annoying them. If

you're sending four messages, 10 messages in MyChart, that's their job is to answer you and to help you feel like you understand what's happening with your disease.

James Hiter (18:33):

Absolutely, for sure. I'm going to shift gears just a little bit and talk about clinical trials. So clinical trials are often misunderstood. How can we shift the mindset about clinical trials in lung cancer?

Brandi Bryant (18:50):

Definitely, of course, advocacy has opened my eyes to clinical trials because I just really had no clue. You think it's an experiment, right? And I feel like more people should know it's not an experiment. This is you're getting the standard of care, plus whatever the latest treatment is that's going to be out. Whenever I started on my targeted therapy, it had only come out of clinical trial a few months beforehand. So thank goodness for those people who said, yes, I'll be on this clinical trial because that medication helps lives moving forward. It can help you and others. So it's not as scary. I love that it's not as scary as we think it is. It's not an experiment. You're still going to get care. You can always opt out if you are not comfortable or if you're not doing well, but clinical trials are what we need.

(19:42):

We have to have them for all of this wonderful progress and research that we're talking about.

James Hiter (19:47):

Without clinical trials, to your point, none of the drugs that we have come to appreciate and have available, none of the therapies would exist. And so I think that idea of normalizing the thought of joining a clinical trial, seeking out clinical trials as an opportunity. I know one of the things I wanted to do was give back. And so I think about clinical trials as a way not only to benefit personally, but also to give back, kind of pay it forward.

Brandi Bryant (20:17):

Yes. And you can ask your physician, you can ask them about, are there any clinical trials available for my type of lung cancer and see what they offer and have a discussion about that. And there are plenty of survivors who've been on clinical trials who'd be happy to discuss what that's like, and it's not something that you should table completely.

James Hiter (20:39):

Well, some of the clinical trials are in fact testing out new drugs, but there are also trials that are testing out other concepts and other things that could be of benefit. And I think for me, my brand of lung cancer doesn't have a targeted therapy, but yet when I was just on chemo and immunotherapy, there was the cocktail of steroids and vitamins and other things that made me feel way better than I thought I would feel while going through. It doesn't take away the fact that you feel pretty bad.

Brandi Bryant (21:12):

Yes.

James Hiter (21:13):

But I knew that it was worse at some point for people that hadn't benefited from those that had gone before me. So from an emotional standpoint, I think people do, and you just addressed this a little bit, I just want to dive into it a little bit more. From an emotional standpoint, thinking about a clinical trial, how would you help somebody alleviate the concerns that they might have related to a clinical trial?

Brandi Bryant (21:39):

Well, we know with the history of this country that a lot of Black people are afraid due to this Tuskegee study, that it's not safe for Black people or other people of color. However, things have changed and they are safe. They're well-designed. They have to go through so many steps. And again, remember that you can always opt out of it, right? Just if there's an option available for a clinical trial, consider it. Discuss the side effects, the benefits that are possibly available with your care team and your family, and have questions, get them answered, and you can make a decision that may be very beneficial to your care.

James Hiter (22:27):

Thanks for that perspective. That's super. When we think about lung cancer, often it's hard to get very far down the path of lung cancer. If you're telling somebody you had lung cancer, you've been diagnosed, we often get to the stigma and this idea that no matter how many of us never smoked, this concept of the stigma and what it's done to research funding and that sort of thing, it's just also deeply ingrained. How do we help shift the focus from blame to biology in lung cancer?

Brandi Bryant (23:06):

I think we honestly need to stop focusing on the stigma because even though there are a large number of non-smokers who are diagnosed with lung cancer, and because some of the best therapies have been working really, really well for us, we still want to increase the screening for those who are at risk. And it shouldn't matter whether you've had a smoking history or not, or whether you lived as a child or you lived with the smoker and you've had secondhand smoke. We have to remember that radon is the second leading cause of lung cancer and other unknown factors that science has yet to answer. So we've got to focus on the person, just like we do with the other cancers. No one's asking for the history of a colon cancer survivor, a pancreatic cancer survivor. We just want to remember we are people. All of us are people with families, with pets, with lives, and we deserve a treatment that works.

(24:06):

And we shouldn't have to ask, "What was your lifestyle like? Oh, but did you do this?" Can we just work and focus on the treatment? Because let's keep this in mind, many of these treatments that are helping lung cancer patients help other cancer patients. So if we can increase the funding, I know that that's part of the stigma. I've also gone on the hill and had a representative directly ask me, "Are you a smoker? Why should we do this if people are smoking?" And it's not about whether they smoked, it's about whether we want to save lives. We want to increase the amount of people that are getting screened who are eligible for screening, and we need the research so that we can have longer lives.

James Hiter (25:00):

Couldn't have said it better. I think about the thing that we all hear in the lung cancer community, which is if you have lungs, you can get lung cancer and for the whole world to know that is truth.

Brandi Bryant (25:13):

That is the truth.

James Hiter (25:14):

And all of the things in your life that you can do that increase or decrease your probability of getting any cancer doesn't change the fact that if you have lungs, you can get lung cancer.

Brandi Bryant (25:27):

Yeah.

James Hiter (25:28):

And this leading cause of cancer deaths deserves to be funded for research the way that other cancers have also been funded.

Brandi Bryant (25:38):

Yes. Yeah. Not only will it benefit us, we know it will benefit others as well.

James Hiter (25:43):

Right on. Well, first of all, thank you. It's one of the most enjoyable things that I get to do with this podcast is talk to people that I already know and love. So it's a lot of fun to spend some time with you, to ask you some questions that maybe we would talk about over coffee, but also in this setting is kind of fun. As we wrap up, can you share with everybody what gives you hope?

Brandi Bryant (26:09):

Honestly, the first thing that comes to mind is these people, these scientists, these doctors, these researchers who are in the lab, in the clinic, interacting with patients, trying to figure out why this does that and how can we stop this from happening? I love that we have gone from, okay, we've got this biomarker, you've got the ALK gene, we're going to... And trying to describe it to someone who's newly diagnosed like how I was like, okay, so basically you've got cancer because this ALK gene is turned on and this pill is going to go in there and turn it off so your cancer stops growing. Okay. Now they're looking into how we can stop progression? How can we make sure that these drugs continue to work and how can we even maybe get a vaccine so we can cure this? I have so much hope, so much hope.

(27:10):

And if we can get that funding up, then we can get these amazing scientists all of the resources they need to cure this thing. Can you imagine?

James Hiter (27:21):

It's an amazing concept. And I said, as much as I enjoy talking to people like you, I look forward to the day when these kinds of conversations don't even have to happen. I would've never met you because neither one of us would've been diagnosed with lung cancer.

Brandi Bryant (27:37):

Right. And I think about the future. I think about my children and how I'm like, oh my gosh, I'm really like, I'm going to be here. My daughter's about to graduate from high school. I'm going to be here for these

things that I thought I wasn't going to be here for. My son calls me dude and bro, I'm getting to enjoy all these moments and make beautiful memories with my children and with my friends and other family that I would not have been able to do if it weren't for those people in the labs and other advocates. I'm just so, so thankful that we have these options and I really hope we can, because we have to keep going. We have to keep going. Now I'm a little bit greedy. It's like, okay, I think I'm really going to make it to 10 years. I'm going to be a 10-year survivor in less than two years.

(28:38):

And it blows my mind from when I was diagnosed to now or to when that is going to happen, for me to be able to think that is definitely going to happen.

James Hiter (28:53):

That's amazing.

Brandi Bryant (28:54):

It's amazing. I'm at the point again where I'm saying, I'm going to be taken out by an acne anvil before cancer.

James Hiter (29:05):

Great picture. Hopefully that doesn't happen, but - I mean,

Brandi Bryant (29:07):

That's the only way they're going to catch me now.

James Hiter (29:11):

Well, Brandy, it's so much of a pleasure to spend time with you, to talk to you. Thanks for sharing your perspective and sharing your hope.

Brandi Bryant (29:19):

Thank you, James. I'm so happy to see you again.

James Hiter (29:22):

Thanks for listening to Living With Lung Cancer: Ask Me Anything. I'm James Heider. If today's conversation was helpful, and I really hope that it was, please follow or subscribe and share the episode with someone who might find it useful. Together, we can really change the way we talk about lung cancer. And if there's a lung cancer related topic that you'd like for us to explore, please let us know in the comments, and you can find a lot more information at lcfamerica.org.