Lung Cancer Foundation of America

I have lung cancer – what now?

Mitch Jelniker:
Hi, listeners, I'm Mitch Jelniker from the Hope With Answers: Living With Lung Cancer team. Today, we're revisiting our very first episode, which tackles the critical question many face after diagnosis: 'I have lung cancer - what now?'

In this episode, Lysa Buonanno shares her personal lung cancer diagnosis story and how tumor marker tests changed her treatment path. Dr. David Carbone, a thoracic oncologist, discusses why he encourages second opinions. LCFA co-founder Kim Norris talks about her work helping patients access the best possible treatments.

A must-listen for anyone newly diagnosed or supporting someone with lung cancer, it provides valuable insights into those crucial first steps after diagnosis.

Please enjoy this informative and hope-filled episode. Now, onto the show.

Lysa Buonanno:
It appeared to look like pneumonia on the X-ray, but in my mind I just kept saying, "But I'm not sick." But yeah, it was scary knowing that something big was probably about to be revealed.

Diane Mulligan:
Lung cancer is a tough topic. It's a disease that affects patients, families, co-workers, but most of all, it's a disease that affects people. I'm Dianne Mulligan with Lung Cancer Foundation of America.

Sarah Beatty:
And I'm Sarah Beatty. The Hope with Answers podcast brings you stories about people living, truly living, with lung cancer, the researchers dedicated to finding new breakthrough treatments, and others who are working to bring hope into the lung cancer experience.

Diane Mulligan:
Lysa Buonanno was in pain. Her back had been bothering her for months.

Sarah Beatty:
She toughed it out to finish her college training as a radiology technologist, but Lisa had no idea that her most important patient would be herself.

Diane Mulligan:

And so, this is a story about how quickly things can change in lung cancer research and some of the things you can do to stack the deck in your favor if you are facing a similar diagnosis.

Sarah Beatty:

So let's start with Lisa's story and how she has used her diagnosis to become a powerful advocate for lung cancer patients and research funding.

Let's start right now with the best news of all. You are eight years out from your lung cancer diagnosis. That's amazing.

Lysa Buonanno:

Yeah, it's really exciting. I definitely didn't think I would make it eight years when I was first diagnosed. So yeah, every day is just amazing that I'm still here with my family.

Sarah Beatty:

What happened to you? What was going on with you that made you feel like, "I need to go get something checked out. I need to see what's happening here"?

Lysa Buonanno:

I had had a back pain that just wouldn't go away. I thought I pulled a muscle and just kept kind of pushing it off and tolerating it and continuing through your daily life. And it finally got to a point I couldn't ignore it anymore. So I went with my mom to the Quick Care Center initially and had a chest x-ray. And just graduating from school as a radiology tech, I looked at X-rays all day long, so I asked if I can see my images. And I didn't know what was wrong with me of course, but I knew my lungs were very ugly and they weren't supposed to look like that. And then, they sent me to the hospital actually to have a bunch more tests done.

Sarah Beatty:

But things had been feeling sort of not quite right for a while?

Lysa Buonanno:

Yeah. For about four months. It wasn't constant pain, but when it would come, it was pretty debilitating. I went to a chiropractor, I got massages just thinking, I was 40 and healthy. I thought I just kind of tweaked my back a little bit, but that wasn't the case.

Sarah Beatty:

I can't think that any reasonable person would think, "Back pain, I better check for lung cancer."

Lysa Buonanno:

Oh, absolutely not. Especially because of what I was doing now in my new career. I was in back surgeries all day long and really just thought, "Worst case scenario, I've slipped a disc. I might need a surgery." Never once did it ever enter my mind it could have anything to do with my lungs.

Sarah Beatty:

And the fact that you participated in your own diagnosis, I don't think that very many people would be able to do something like that. What did that feel like?

Lysa Buonanno:

I wasn't sure, like I said, what it was, but I knew it was probably something pretty serious. It appeared to look like pneumonia on the X-ray, but in my mind I just kept saying, "But I'm not sick. I don't have a cough, I don't have a fever." And other than the pain physically I felt pretty decent. But yeah, it was scary knowing that something big was probably about to be revealed.

Sarah Beatty:

You mentioned your mom. What was your family situation at this point? You were kind of onto a second act right in your life, and graduated from school and starting a new career. What was that like in your life at that moment?

Lysa Buonanno:

My kids, my son was 19, my daughter was 11. My husband was working a ton of hours so I could go to school and not have to work. And I had this whole new plan, this path of how things were going to go now that I'd graduated. And this was just a devastating blow, not just the diagnosis, but that your life is about to completely change. I no longer was able to work. I couldn't work in this career that I really loved and worked so hard to get a degree. Going back to school at 40 years old isn't easy. Your brain doesn't quite function the way it does when you're 20. So yeah, it was pretty devastating. You don't expect that. It's not obviously anything we plan for. And you feel like the rug has just been pulled out from under you,

Diane Mulligan:

And I think that that's so important to share that to anybody who might be listening who is in that spot, in that space. Talk about what it feels like when you're in that space and the doctor has just said, "Well, I'm sorry to tell you, you've got lung cancer." Do you hear anything after that, anything the doctor might say? Or does your brain kind of go...

Lysa Buonanno:

Yeah, I think everything else kind of becomes a little muffled after that. I unfortunately had lost a really good friend just four or five months before that to lung cancer and she was 44. And so, that was something that entered my mind as well is that was kind of my only experience with lung cancer. I didn't really know a whole lot about it. And watching what happened with my friend in a short amount of time, my first thought was like, "Oh my God, that's what's going to happen to me. I'm not going to live very long with this disease. And who's going to raise my kids?"

And to look my husband in the eye and have to tell hi, he wasn't with me. My mom went with me to the hospital and we immediately broke down when he told my mom, "You need to sit down." And it was the ER doctor that gave us the diagnosis that, "You have lung cancer and it's already spread to your spine." And I knew what that meant. I knew that meant Stage 4. I knew the prognosis was not good. And to look my husband in the eye and have to tell him that all of our plans for our future are probably not going to happen.

And it was scary too, not knowing much about it, not knowing... I kept, "Why? Why did I get this? I'm super healthy. I try to do everything I can to take care of myself." And of course, it wasn't until later educating myself, learning that anyone, literally anyone can get lung cancer. And that wasn't anything I was aware of at the time. So I just kept questioning and reading, research everything to death wanting to find the why and how can I protect my family? If this can happen to me, it can happen to them. So just a whole whirlwind of emotions and feeling alone, like, "I'm 40 and I have lung cancer?" I didn't realize unfortunately how many really young people are diagnosed with lung cancer.

Sarah Beatty:

What I want to hear from you now is if someone is in the same position right now that you were in eight years ago, as someone eight years out from your lung cancer diagnosis, what would you tell someone right now? What would you tell them to do?

Lysa Buonanno:

Initially, in the beginning, I tell everyone to make sure you're getting biomarker testing. It's absolutely critical to have done in the beginning. They're already doing a biopsy, so to make sure they're getting enough tissue so they can do additional testing. That it can really-

Sarah Beatty:

Let's explain what a biomarker test is.

Lysa Buonanno:

Sure. Biomarker is just a marker, something that shows up within your tumor tissue that drives your cancer to grow. So just like we've heard about other biomarkers for breast cancer, say that help drive those cancers to grow, there's a BRCA gene, a HER2 gene, and they have the similar types of mutations in lung cancer. So if they're able to determine that you have one of these, then it just kind of gives you a better idea of what treatment options are most likely to work for you.

Sarah Beatty:

And biomarker testing is something that can be done, because like you say, they're going to biopsy this tumor anyway, so they've got a bit of tissue.

Lysa Buonanno:

Yes.

Sarah Beatty:

And so, you should be making sure that as they're looking at that tissue, as your oncologist is looking at it, that they're going to run a biomarker test to see if there are certain mutations that are eligible for a particular drug, a targeted therapy.

Lysa Buonanno:

Yeah, absolutely. And this is fairly routinely done at a lot of the larger academic centers in bigger cities, but it is unfortunately not done automatically at some of the smaller community cancer centers, or even it might even be your pulmonologist that has sent you for these tests. So it's critically important to educate the patients very quickly in their diagnosis to make sure that there's not a delay that these tests are being done.

Sarah Beatty:

But really from the patient perspective, I want to hear you give your best advice about taking your time at this point.

Lysa Buonanno:

That's exactly what goes through your head. That's what you're feeling is. "Okay. Well, we need to tackle this now. What do we do?" You want to get started right away. And there was a lot of waiting going on in the beginning of this. There might be waiting to get your initial diagnosis even and then to get results back from biomarker testing. But even if it does take you a couple extra weeks to get that information back, you know you're making a better informed decision by having all of the information.

I know in the beginning when I was first diagnosed, biomarker testing wasn't very common eight years ago. I had to have a surgery first because of complications, but immediately jumped into chemo and radiation. And that was at the time we thought my only option anyway. But even then, because I had to wait till my spine healed from my surgery several weeks before I could start radiation to that same area. And to me, that felt like forever, just those few weeks. And we already had a plan. So I understand waiting and not knowing what your plan is, but really, like I said, you can't make a good informed decision without knowing what all your options might be.

And it took a long time in most cases for your tumors to get to the point they are now. So waiting a few more weeks, you most likely are not going to have any dramatic changes in that time. And granted, there are people that it's necessary. They do have to start a treatment right away, maybe based on symptoms or something they have going on. But most people really can afford to wait those couple extra weeks to make sure you have all the right information.

Sarah Beatty:

And so, when your biomarker test came back, which I should note was like a year and a half later.

Lysa Buonanno:

Yes.

Sarah Beatty:

So you had chemo, you had radiation, you had surgery, which we all have heard about and would sort of expect. But it was about a year and a half later. Tell me what happened that caused you to get the biomarker testing and what happened after that.

Lysa Buonanno:

I was lucky. I had a really great response to the chemo and radiation initially, so we just kind of rode that wave until it didn't work anymore. And once I did start having progression, my oncologist at the time only offered me another chemotherapy. And I had educated myself a lot in that 18 months and connected with other survivors through online communities. And everyone stressed, "You have to have biomarker testing done." And I fit the profile. A younger never smoker woman is much more likely to have one of these biomarkers.

So I decided we needed to find another oncologist. I needed to find somebody who was going to fight a little harder for me and maybe someone that had a little more experience with lung cancer. So it was at that time I found another oncologist, and the first appointment he sent me for new biopsies, but they kept coming back inconclusive. So by the next appointment he actually called the thoracic surgeon and said, "I think we really need to have this done. I think it's going to require a surgery to be able to get in and access that tumor." That's how important he thought this testing was. And I was very, very lucky to come back and have one of those biomarkers. I tested positive for ROS1, and my oncologist actually called me at 10 PM really excited. "We got the results and you're ROS1 positive." And it was just a little bit of a relief knowing that I had another treatment option out there.

Sarah Beatty:

So there's a couple points in there that I really want to make sure that we revisit. One is the idea that you built a relationship with that new oncologist, that you've found someone like you say, that will fight a little harder.

Lysa Buonanno:

Yeah.

Sarah Beatty:

Who has some specialized information. So let's talk really quickly about the difference between an oncologist and a thoracic oncologist or what we could just call a lung cancer specialist, right?

Lysa Buonanno:

Yes. A general oncologist is kind of like your general practitioner. They see a little bit of everything. And the thoracic oncologist specializes in cancers that live inside your chest area, so it could be lung cancer, lymphomas, anything that originates within your thoracic region, your chest area. And they are just way more likely to be up to date, especially in the lung cancer field right now where things are just seemingly to change every couple months as far as treatments go. So you really need someone that has a lot more knowledge in that particular arena.

Sarah Beatty:

Right. And so, ROS1 is one of those mutations that has a drug for it, right?

Lysa Buonanno:

Yes.

Sarah Beatty:

What's that?

Lysa Buonanno:

Xalkori or Crozotinib was originally approved in lung cancer for the ALK mutation, and they discovered it also worked really, really well for the ROS1 mutation. So a couple of years after being approved for ALK, it also got approval through the FDA to be treated for ROS1 mutation cancers as well.

Sarah Beatty:

What's the difference? What does it feel like the difference between chemo and radiation and taking a targeted therapy? How different are those treatments?

Lysa Buonanno:

Very, as far as the way you feel. These targeted therapies are also in pill form. You're taking them at home. You don't have to go to a hospital or a clinical setting and get an infusion for multiple hours every few weeks. My particular one I take twice a day. They do have their own list of side effects for sure, but there's a lot of good tricks we've learned, I guess, over time to deal with these side effects. And they're much more manageable and easier to deal with as far as chemo goes. And I feel pretty good most of the time. A lot of GI stuff: nausea, diarrhea, sometimes constipation. But other than that, I really feel pretty good on this drug and I'm able to still live a normal and active life.

Sarah Beatty:

So the difference is you're taking two pills a day and dealing with some side effects, but manageable side effects versus sitting in a hospital or a clinic taking a treatment that makes you feel terrible.

Lysa Buonanno:

Yeah, absolutely. I'm actually doing chemo again now, and it wipes me out for a good six days. The fatigue is when you say you have fatigue, people are like, "Oh yeah, I'm really tired too." It is just something you can't explain. I literally rarely move off the couch or my chair. I kind of bounce back and forth over those days. I try and get a couple meals in a diet. It's hard to eat. I don't have nausea because of medication, but I have no desire to eat anything whatsoever. And I sleep 12 hours a day during chemo. So it's definitely rough.

It takes a toll on you mentally too I think when you feel so bad physically. I have a mantra I repeat all the time, "This is temporary." I have to remind myself, "I am not going to feel like this next week. This is temporary." And you just kind of count down the days, because I know I have infusion on Wednesday, and by Tuesday I feel good again. It's almost like you flip a light switch. But dealing with the targeted therapies really is, it's life changing really. You're able to continue your life and still be active and still do stuff with your kids and not have so much downtime.

Sarah Beatty:

Right. That's the amazing thing, I think. And that's a possibility that's opened up once you access that biomarker testing potentially if you have certain mutations.

Lysa Buonanno:

Yeah, because they're not going to work for you and control your cancer if you don't have one of those mutations. But even if it's discovered that you don't have one, that's okay too because now it's telling you, "Okay. Well, now we know this class of drugs doesn't work. But we know this is likely to work for you." So I know some people are, you're hopeful that you might have one of these mutations. And not everyone does, obviously, but it doesn't mean there's not still good treatment options out there for you. But you don't know that without the testing.

Sarah Beatty:

So it's kind of something that sets up the game plan like, "Now we have this information. Now we've narrowed down the options and we've got a plan going forward."

Lysa Buonanno:

Yeah, exactly. Otherwise, it's just kind of guessing. They're like, "Oh, we'll throw chemo at you and see how that goes." And we don't unfortunately have the liberty of time most of the time. We can't waste two months doing chemo or any drug that we know is not going to work because then you just have the potential for growth, obviously. And we don't have that kind of time to waste.

Sarah Beatty:

So speaking of time, I think it's important that everyone understand that lung cancer is a different beast. So if I'm diagnosed with breast cancer and I do treatment or do surgery, there's a really good chance that they will catch that cancer and I can go on about my life after treatment and not really have to deal with it again. And that's not the case with lung cancer.

Lysa Buonanno:

True. The majority of lung cancers are diagnosed at Stage 4. You have less treatment options available. You are considered at this time incurable. It doesn't mean we can't manage the disease, but even with these targeted therapies, cancer is very smart. It finds a way to work around these treatments and it does become resistant to these drugs. So we are constantly needing new treatment options for when that time comes. And it can be very hard to control for a lot of people, and unfortunately is considered terminal for the majority of us diagnosed with it.

Sarah Beatty:

LCFA along with its partner organization, the IASLC is dedicated, it's founded to raise funds for lung cancer research. And you just touched on why that is so important. Talk about what it's like to be waiting for research to buy you another 18 months, another three years, another five years.

Lysa Buonanno:

It's very nerve-wracking. They have come a long way, like I said. They have so many new treatment options in the last five to 10 years. So that alone is really exciting and is hopeful. It's hopeful that you're right on the edge of them discovering another new treatment option.

In my case, because ROS1 is so very rare, there's not a lot of studies being done on it because it affects such a small number of people. So I'm on my last available treatment option right now. And I'm very blessed. I just had scans a few weeks ago and I'm still stable. And I know that is not going to remain the case forever and I will need another treatment option. So knowing that there's brilliant minds out there working on this is really, really hopeful for me. But it's also a little scary. Science needs to stay ahead of my disease. So I'm just hoping that when the time comes, there'll be something else out there for me. And that's why research really is so critically important. And organizations like LCFA are critical to funding this research, because the federal dollars allocated to lung cancer are pretty minimal compared to the mortality rate of lung cancer.

Sarah Beatty:

And part of your work now is as a patient advocate, partly helping other patients, talking to people who've been diagnosed and helping them, partly working in the ROS1 community, and then partly trying to help people understand, make that connection between the need for research funding and being able to access new treatments that might help someone like you. So tell me about how you came into patient advocacy and what that means to you.

Lysa Buonanno:

Well, originally when I was diagnosed, I just started searching online to find information. My mom found a local walk that was coming up soon after diagnosis. So we decided, "Oh, well, this is a way to kind of jump in and dip our toe in and get involved a little bit." And it went from speaking at that walk, learning about the low funding amounts for research and being angry that, "I can't believe it kills this many people a year and no one seems mad about it. Why aren't they getting more research dollars? Why isn't more being done?" And I found that that was a way for me to use my stubbornness, to use my tenacity to kind of share my story and my voice to help make a difference hopefully, and get some more funding.

And then also, I like being connected to newly diagnosed patients, especially now being eight years out, to give them hope that, number one, that's a possibility. You can be here years later. And to help guide them, like I said, make sure they know about biomarker testing. If they're not happy with their oncologist or facility, I've been blessed working in advocacy to meet top doctors all over the country and amazing patient advocates in almost every other state. So even if they're not in my state, I can connect them to someone that can help them or guide them in their state. And I wish I had that in the beginning. So that's something I feel is really important for me to be able to have a way to give back and help others.

And also, I needed to find my new normal. I needed to find a purpose for my life at the time. "I'm no longer working, what else can I do? How can I try and make a difference for other people fighting this disease?"

Sarah Beatty:

I am just in awe of your energy and your dedication and your commitment to this. Tell me what helps you see your way through this? What helps you remain positive and have a clear-eyed understanding of what you're facing, but also a hopeful attitude?

Lysa Buonanno:

That's tough sometimes. Really being connected with other survivors has helped me a lot. It's people I can talk to and vent to. I can text in the middle of the night and just kind of share my thoughts, my fears, and know that they just get it. And that's really helpful to me mentally, honestly, to be able to... I'm very realistic. I'm not likely to live to be 80 years old. But I'm also really hopeful because research really is something that gives me hope. But also having connections with these other advocates and even other oncologists across the country, knowing that we are all in this together and we're trying to do... So many amazing different advocacy groups really are trying to do everything we can to make lives better for those living with lung cancer. So I just choose to be hopeful and look at things in a little more positive note.

But definitely, there are times where I break down and cry. There are times where I'm like, especially regarding research, "Am I wasting my time? Is anybody really listening? Are we really making a difference?" But then unfortunately, you'll have someone in your community pass away. We've had a lot of young women recently pass away in the last month, and that just kind of fuels your fire a little bit more, like, "If we don't do this and keep making noise, then who's going to?" So that's really kind of what keeps me focused on trying to just keep moving forward.

Sarah Beatty:

One of the projects that you work on is called Hope with Answers. And it was so fun when we worked on it together at World Lung. And one of the kind of rock star young researchers from Johns Hopkins, Kellie Smith, walked in the room and we're all sort of in awe of her because she's just amazing.

Lysa Buonanno:

Yes.

Sarah Beatty:

And do you remember what she did? She took out her phone and she said, "Can I get a picture with you guys?"

Lysa Buonanno:

Yeah. She was like, "Can I have a selfie with you guys?" And we were like, "Yes, we want a picture with you."

Sarah Beatty:

That to me just was such a cool moment to have, this incredible scientist, researcher, young woman herself. As a matter of fact, I talked to her the other day. She's got a brand new little baby, her second. So she's a young woman herself who is on the absolute cutting edge of lung cancer research partly because of this LCFA grant for her work. And here she was walking in the room so excited to work with patient advocates and survivors on the Hope With Answers project. Tell people what Hope with Answers is and why you're involved in that.

Lysa Buonanno:

I've worked on a lot of different projects over the last few years, and this has by far been one of my favorite. So Hope with Answers is a online video series, and it just really explains those questions that we all have as survivors, patients. And we don't always either get to ask them with your doctor or you forget about, or they come up later when you're not there anymore. Or you might hear online keywords like biomarker testing and what is that exactly? So Hope with Answers is patients asking these top doctors and researchers these questions that we all want to know. Especially in the beginning, you have so many questions and it's very confusing. Learning about lung cancer is like learning another language.

So they have it broken down into three steps. You have the very basic, just explaining what is biomarker testing? And then, you have the intermediate section where it goes a little bit more in depth and maybe things you could bring up to have conversations with your oncologist. And then, the third more advanced interviews are really getting in-depth about specifics regarding biomarker testing.

And we have probably a dozen different categories now. We have clinical trials, surgeries, and you can go online anytime of the day or night and see these patients interviewing top doctors that we would normally not have access to. So I just think it's great. It was a lot of fun working on it, working with these amazing doctors and Kellie. We're in awe. They're our rock stars really. We put them on this pedestal of, "You're the person that might find my next big thing out there." So it's really encouraging too to hear them excited about what's going on in the research field. So I just think it's an amazing project and was really, really fun to be able to work on.

Sarah Beatty:

And people can find those videos at hopewithanswers.org. They're also on the LCFA website, LDFAmerica.org. And that's how I've gotten to know you and a number of these other amazing lung cancer patient advocates in your work and these doctors. And I just geek out every time I get to talk to these docs.

Lysa Buonanno:

Me too. They're so cool.

Sarah Beatty:

Well, thank you so much for your work, for your willingness to share your story, and for everything that you do to help make a very upsetting diagnosis easier on other people, other families. I just can't tell you how much we appreciate everything that you do.

Lysa Buonanno:

Well, thank you very much. It's really my honor to be able to participate.

Diane Mulligan:

Up next, we'll talk to a lung cancer specialist about the importance of a second opinion and how to get one.

We hope you're enjoying the LCFA Hope with Answers podcast. It's produced as part of our nonprofit mission. The support and expansion of lung cancer research accomplished by raising funds that serve to one, increase the public's awareness of lung cancer status as the leading cause of cancer death, two, to inform and educate lung cancer patients in their lung cancer journey, and three, fund innovative lung cancer research.

Welcome back to the Hope with Answers podcast. Now we're going to talk about, "I've been diagnosed. What now?"

Sarah Beatty:

Absolutely. What now? We've been talking to Lysa Bunonno to help answer that question. She's a lung cancer patient and advocate, and we've been talking to her about how important it is to get a second opinion.

Diane Mulligan:

So hopefully one of your next conversations is with someone like our next guest, Dr. David Carbone, a Professor of Medicine and the Director of James Thoracic Center at the Ohio State University.

Dr. David Carbone:

I've been in practice for 30 years. Oncology was much simpler and there were a few drugs available. There wasn't a lot of reason to pick one over another. And the pathways for treating different cancers were quite simple and frustratingly ineffective actually. But in the last decade especially, there's been dramatic progress in the therapies available and in the analyses that are important to be done for different cancers in order to make the right treatment decisions, types of testing that have to be done before treatment decisions are made. And so, it's become very difficult for an oncologist that sees every type of cancer from lymphoma to colon cancer, to prostate cancer, to breast cancer, to bladder cancer, to lung cancer, to stay up to date in the details of optimum management for particular cancers.

So these are generally excellent doctors who perform a really important service in their communities. But I think with this rapidly changing and complex field of cancer management, I think it's important to know whether your doctor specializes in lung cancer or not. And it's a little bit hard to judge sometimes, but often if you're seen in an academic medical center, at our medical center, for example, we have seven medical oncologists that see only lung cancer. And because of that, they stay up to date very effectively. And they know the latest things that are out there, the things that are coming soon. They are versed in the various tests that need to be done. And it's not uncommon that we get a second opinion from a general oncologist and we agree with their plans, and that's fine. But it's also not uncommon that we say, "Well, maybe we should test for this genetic abnormality or maybe we shouldn't use that drug. There's a new one that we have in clinical trial that's looking a lot better."

So as a general message to lung cancer patients, especially if you're being seen by a general oncologist, no matter how much you like the guy or how convenient he is, before starting treatment, I think it is important to reassure yourself that you're getting the state-of-the-art care by getting a second opinion with a specialist.

Diane Mulligan:

I think that's really helpful information for people when they're in that spot of just having been told that they have lung cancer. And something that you talked about in February when we had a meeting was this sense of sort of panicked urgency like, "I have been diagnosed. Now I need to do something now. I don't have time to wait for a second opinion." And I'd like to revisit your advice that you gave people about that sense of needing to do something immediately versus waiting for the second opinion. "Do I have time to wait?"

Dr. David Carbone:

Yeah. Well, it's completely understandable the frame of mind that patients are in when they get that diagnosis of lung cancer. One day, the biggest concern they have is what to make for dinner or what to do on Saturday night. And then, the next day they're being barraged by tests and whisked one way or another and poked with needles. And people are talking to them in a foreign language, and they look up lung cancer on the internet and they see how bad it is. There's a panic that sets in that's completely understandable. And sometimes, unfortunately, doctors feed into that.

But the fact is, that it's better to do the right thing than the convenient thing. And with the current state of the art of lung cancer therapy, it's absolutely essential to have a variety of testing done on the tumor, which sometimes takes a week or two or three to come back, before an informed optimum decision can be made about what the best therapy is. So I think it's really important for both the physician and the patient to understand that these tests should be done before a treatment is initiated.

And I usually tell patients that even though you've just found out about this cancer, the average time for a tumor to double in size with lung cancer is two to 300 days. So that the tumor is likely to have been there for many months and an extra two weeks to make the right decision about therapy is really the smart thing to do. So I refer to it as being a psychological emergency rather than a medical emergency.

And the other thing is often when you do get a second opinion, sometimes the local oncologists will say, "Well, let me just give you a dose of chemotherapy while you're waiting a week to get your second opinion." That is really a bad approach, because that eliminates you from any clinical trials for that setting, and may result in a complications when if you find, say, a targeted therapy approach and they've already been started on chemotherapy. I think that's not an optimal way to go. So really, in most situations, it's safe and in fact smart to wait to get the complete picture of what's going on before treatment is started.

Diane Mulligan:

That's the value of the second opinion, is having a lung cancer specialist sort through these options based on the exact type of tumor you have.

Dr. David Carbone:

Also sending the correct tests. Sometimes no molecular testing is done at all. Other times just two or three tests are done. But now there are six or eight different molecular features of cancers that really completely changed the therapy approach. So it's also being reassured that no stone has been left unturned to find highly effective therapy targets as well as knowing the latest drugs. We are fortunate right now to be in a situation where we now are on second, third-generation drugs that are much more effective and less toxic than the earlier generation drugs. And sometimes the community oncologists may not be aware of what's available.

Diane Mulligan:

One other thing that we hear a lot from lung cancer patients early in their journey, but feeling like, "I don't want to offend my doctor."

Dr. David Carbone:

Yeah.

Diane Mulligan:

"He or she's been super nice and super helpful and very reassuring, and how do I go in and say, 'Thank you, doc, but I really want to go see another person' without offending them or without feeling like somehow you're compromising your care down the road. Or am I asking my oncologist to collaborate with another doc that he or she might not know?"

Dr. David Carbone:

Right. I think that's also a totally understandable sentiment. But I think when you are diagnosed with advanced lung cancer in particular, or any stage of lung cancer, you need to focus on what's best for you and not your doctor. Your doctor is not getting treatment, you are. And they should not feel threatened by their patients getting a second opinion. You can do it in a nice way, and the patient can tell their doctor that, "I have heard there's new treatments out there. I just want to investigate a little further and be sure that we're on the right track here."

And like I said before, it's not uncommon for me to do a second opinion and review what's going on and say that, "This is great and I totally agree with your oncologist, and you should get treatment from your regular oncologist." It's also not uncommon for us to do some additional testing and find a target and then be able to recommend an FDA approved drug that could be given by the first oncologist. But then, it's also common that we would have a clinical trial that is really exciting and might be something that wouldn't be available. What I often say to patients is that if their oncologists tries to fight them in getting a second opinion, then they definitely need a new oncologist. And a good oncologist will welcome a second opinion.

One other aspect to this is that you really do need one captain of your ship, is the way I usually portray it; that you can't get treatment by one doctor being directed by another. You can get a second opinion, but at some point you need to pick who your doctor is and that's your doctor. I do think it's unfair to say, "Well, I'm going to get treatment by my doctor, but I'm only going to do things that some other doctor tells him to do." I don't think that's a good plan. You get the two recommendations. You make your decision about who your doctor is going to be. You share the recommendation between the two doctors, and then you just get treatment from one doctor as your main doctor.

Diane Mulligan:

Is an academic medical center the place to start or their current oncologists? Or how would you go about that?

Dr. David Carbone:

Well, it is impossible to generalize. There are large private practices that have outstanding thoracic specialists with clinical trial availability. And then, there are academic centers that have really bad thoracic oncologists. So it's difficult to generalize. But I think in general, an NCI designated cancer center will have a respectable ability to see thoracic oncology patients. But beyond that, what I often say, especially in more rural areas, is to ask if their doctor is a member of the IASLC, International Association for the Study of Lung Cancer. In my experience, even private practice doctors that show enough interest in lung cancer to be a member of that organization can be trusted to be up-to-date in their recommendations. So I don't think that specialists are exclusively at academic centers. It's just often easier to find them there.

Diane Mulligan:

What is your best advice when you get someone who comes to you for a second opinion and looking for honest information, but hopeful information? What do you tell someone who's coming to you for that second opinion?

Dr. David Carbone:

Well, I'm always honest with my patients. That's not a variable in this equation. But I do tell them what I think about the management that they've had and what I would do next. And I actually really try to see in their own situation what would be best for them, whether local treatment would be better. I have many patients who come from multiple hours' drive away, and if my recommendation is a standard FDA approved regimen, I think that I'd send a note to their doctor or call them and say, "This is what I think" or "I agree with what your plan is."

But then I always tell my patient, even if I don't plan to give them therapy, I tell them that, "Once you're my patient, you're always my patient." And that if there's a question on a scan or if there's a problem or the tumor becomes resistant, they're welcome to just call and make an appointment and I'm happy to re-review the case and make additional suggestions so that they don't feel like it's a one-and-done, and I'm abandoning them; that I am happy to give advice at several points in their cancer journey.

Diane Mulligan:

I think that's a wonderful way to phrase that, and it strikes me as sort of touchy-feely as this might be is building a relationship with your care team of people that you can rely on and trust and go to for more information or questions or help.

Dr. David Carbone:

Well, you certainly have to trust your care team. You are in a situation where you have a life-threatening disease, and often patients get randomly assigned to a doctor who's going to guide their therapy and potentially determine whether they're going to be cured or die of their disease. And it's very possible that you may not develop that trust immediately in the doctor that's randomly assigned to you. I'm a cancer survivor myself, and I often say that there's a big advantage to being a cancer doctor in that situation because you know the language, but you also know colleagues that you trust. And so, you have instantly a trusting relationship with your doctor, which doesn't happen immediately when you're randomly assigned to someone, but is extremely important.

Diane Mulligan:

Well, thank you so much. I know you are so busy every minute of every day, and I really appreciate you taking the time out of your schedule to talk through some of these things and to help people understand the importance of a second opinion and the information they're trying to get out of it. So I'm really grateful.

Dr. David Carbone:

I'm very, very happy to do it. I think it's really important to get the message out there that it's complicated and scary, but there's real hope today for a long, high quality life with lung cancer.

Diane Mulligan:

Want more Hope with Answers? Visit us online at LCFAmerica.org, where you can find out more information about the latest in lung cancer research, new treatments, and more. You can also join the conversation with LCFA on Facebook, Twitter, and Instagram.

Sarah Beatty:

Welcome back. We call this podcast Hope with Answers because we can honestly say there is hope in the face of a lung cancer diagnosis today.

Diane Mulligan:

That's absolutely true. And we want to check in with LCFA President and Co-Founder Kim Norris on her best advice for someone who's just diagnosed with lung cancer. So Kim, thanks so much for being with us.

Kim Norris:

Glad to be here, excited for what we're doing here.

Diane Mulligan:

Oh, me too. We had a conversation just recently that in the past week you've talked to more than three people about second opinions and how important they are. So tell me why you think they're so important.

Kim Norris:

Probably the main reason is the speed at which the landscape of lung cancer research is happening, all for the best. New treatments, new discoveries are happening at breakneck speed. And it's really hard for any one oncologist, especially if they're a general oncologist, to be able to keep up with everything that is happening in the lung cancer arena for treatment. So ideally, getting a second opinion with someone that is an expert in lung cancer, what I like to call a thoracic oncologist, who lives and breathes lung cancer, they're the ones that are going to be up to speed and know the latest and greatest for you.

Diane Mulligan:

So you've just had this diagnosis, Kim, and what an emotional situation that is. And you've shared that with an oncologist who you've sat across from. And I'm thinking that immediately there is possibly a comfort, or at least you're comfortable with that doctor. The thought of going to get another doctor, finding the right doctor, I would think that could be somewhat overwhelming and there might even be some loyalty issues in there. How can people deal with that?

Kim Norris:

Well, yes, and I understand that. There are loyalty issues involved there. But you know what? We're talking about your life, and it's important that you get the best information you can before you make that decision on what that treatment should be for you. So the first thing I would tell you to do is take a deep breath, slow down. Chances are great. Most of the lung cancers we deal with are slow growing. I know you have this urge to do something immediately and get it out right away. But in most cases, unless your health is at risk in that moment, you have time to do your homework and get educated and make sure that you pick the right option for you. It's the right treatment for the right person at the right time, and that's what we want you to find.

Diane Mulligan:

And I'm also guessing that it may also help if you have someone who can help you through this process who can do some research for you, who is a shoulder that you can lean on in this situation. Would you agree?

Kim Norris:

Absolutely. That's critical. I've gone through some of my own medical issues recently, and I do patient advocate work all the time. But when it comes to me, I become a blubbering idiot and I can't hear what they're talking about.

Diane Mulligan:

Right.

Kim Norris:

So having someone, a loved one, a friend, family, helping you through this and doing some of the heavy lifting, that makes all the difference in the world. And what you hear may be different than what they hear, and it's important to compare notes on that. Someone else can be reaching out and trying to find where would be a good place to go to get a second opinion. It doesn't all have to fall on you, nor should it.

Diane Mulligan:

Absolutely. What are some of the steps that you should take if you're looking for a doctor to give you a second opinion?

Kim Norris:

I would first and foremost try to find what I call a thoracic oncologist, someone that lives and breathes lung cancer only. Again, the science is happening so rapidly, all to the good, all which is great for you and the patients. That's number one. Where do you find those? So first off, if you have an academic center within reach of you, chances are great a medical academic center will have a thoracic oncologist. So I would go there. If not, probably one of your bigger local community hospitals should also have some thoracic oncologists who specialize in lung cancer. So I would try that first and foremost. And of course, there's always the NCI, National Cancer Institute List of Comprehensive Cancer Centers. They're kind of the crème de la crème of cancer centers and research that's going on. And that doesn't mean you have to get treated at any of these places, but you can at least get educated to make sure whatever treatment choice you pick is the right one for you.

Diane Mulligan:

And all of this is so important, again, because you keep talking about the breakthroughs that are happening constantly and keeping up with them. That all leads to a lot of hope, right? It really makes a difference.

Kim Norris:

I've been doing lung cancer patient advocacy for about 16 years now. I lost my husband 20 years ago to lung cancer at the age of, he was 47. None of these breakthroughs existed back then. And when I started doing advocacy work, I would talk hope, but there was nothing behind it. It was just a word. Now with everything that is going on, not only is there hope, you have options. You can decide which treatment may be best for you. And it's just incredible and exciting, and I can't tell you how many patients now are living five, 10+ years, living wonderful lives with lung cancer because of the breakthrough in science and research.

Diane Mulligan:

It's such a great message and it's so much what Lung Cancer Foundation of America is about. So as the founder, thank you, because there is such great hope out there and we really enjoyed talking to you today.

Kim Norris:

Thank you and thanks for Hope with Answers. I think it's great.

Diane Mulligan:

Through the generosity of donors like you, LCFA is able to fund cutting edge research that will lead to new treatments and protocols with the goal of greater survival rates for lung cancer patients everywhere. We can't do it without you. Consider making a donation by visiting LCFAmerica.org and clicking on the donate button.

Sarah Beatty:

Thanks for joining us today on Hope with Answers. I hope you've had a good time listening to this podcast and found some great information in these conversations.

Diane Mulligan:

And thanks to Lysa Buonanno, our friend living with lung cancer, and a speaker for the Lung Cancer Foundation of America, Dr. David Carbone, Professor of Medicine at James Thoracic Center at the Ohio State University. And Kim Norris, President and Co-Founder of LCFA. Thanks for joining us on Hope with Answers. We'll see you again soon.