Understanding ROS1 Positive Lung Cancer: Treatment Advances and Hope Transcript

Annabelle Gurwitch (00:00):

When I heard the word hope when I was first diagnosed, it just made me angry. 'cause I felt like, oh, am I supposed to hope? Like, sort of like that made me, I heard it like, sort of like thoughts and prayers where it seemed like an ephemeral or something not to hang onto. But now when I think of the word hope, I think about, uh, advancements in science. And I oh, hope is actually looking and seeing at the advances. And even since I was diagnosed five years ago, the advances are amazing.

Ava (00:31):

Welcome to LCFA's, Living With Lung Cancer: Ask Me Anything podcast where we have real conversations with people living with lung cancer. Learn from personal journeys and expert insights. Subscribe now and never miss an episode.

Annabelle Gurwitch (00:54):

This is Living With Lung Cancer: Ask Me Anything. I'm Annabelle Gurwitch, your host today on this podcast we're having. The kinds of conversations that I wish I'd been able to have when I was diagnosed were sharing practical strategies as well as talking about the emotional impact advances in science, community, building our challenges, and even how we're cultivating joy while living with lung cancer. If you're a patient caregiver, you belong here. Welcome, Dr. Shaw. We're gonna talk today specifically digging into one of the kinds of what we call oncogene driven lung cancers. So first of all, let's talk about what that means. When, when you're, when you're diagnosed with lung cancer and you're told you've got an oncogene driven lung cancer, you say, I have no idea what you're talking about.

Dr. Alice Shaw (01:51):

Yeah, so if you're told you have an oncogene driven lung cancer, that's generally good news. So we'll start there. Um, but typically what that means is that your oncologist has done molecular or genetic profiling of your cancer, and they've identified an alteration that has now turned on a gene abnormally. And that abnormal gene is now driving the growth of your cancer. And it's important because now we have many different ways, specifically targeted therapies that can turn off that abnormal gene.

Annabelle Gurwitch (02:21):

Right. So, you know, for someone like me who was diagnosed five years ago, I was diagnosed with EGFR mutated lung cancer, uh, non-small cell lung cancer. There's two kinds of lung cancers in general. Small cell, non-small cell. Um, for anyone who's just been diagnosed, that information can be really important. 'cause all of a sudden, you know, when we're anyone who has any reference with cancer, for instance, I just thought there was like lung cancer, uh, uh, breast cancer, I, no idea there were all these categories, but this is the kind of information finding out you have one of these oncogene driven cancers. This is the kind of way that science has advanced in the last, what is that 15 se 15, 17 years? Uh, you know, for

someone who gets diagnosed with that and has an oncogene driven lung cancer, uh, that is actionable. And by actionable we mean that there's a drug that can, uh, work with that. So this is what an EGFR mutated lung cancer is, and there's other kinds as well, and, and this makes all the difference in terms of kinds of treatments.

Dr. Alice Shaw (03:37):

Absolutely. This is really critical information, and this is new from 15, 20 years ago when we didn't do molecular testing. This molecular testing is considered routine. It's considered standard of care. Every patient, um, with non-small cell lung cancer, especially adenocarcinoma, should undergo this molecular testing. And the reason is this, if you have an oncogene driven cancer, that means you have a molecular target in your cancer. We need to know that so that we can select the best therapies for the patient.

Annabelle Gurwitch (04:10):

Right. So you're someone who's listening to us now or watching us now who's just been diagnosed and they're like, you hear all these words, it's like a word salad when you hear this, but we're talking about something that's a, a standard protocol

Dr. Alice Shaw (04:27):

That's correct.

Annabelle Gurwitch (04:28):

To be tested to see if we have these mutations that could qualify our kind of cancer for these treatments.

Dr. Alice Shaw (04:37):

Yes. So, that profiling is essential to determine what type of lung cancer a patient may have, and then to identify the best treatments. And that's why this testing is so critical right

Annabelle Gurwitch (04:48):

Now for someone like me who started treatment at a major center in a major city, that's what I was told. I didn't have to ask for that testing. But we know there are people out there who have to ask for that testing. Um, and what do we tell you, what do you advise people to do? How do you advise a patient to do that? What language do they use?

Dr. Alice Shaw (05:13):

They should ask mm-hmm

Dr. Alice Shaw (05:14):

Um, they can ask about the results of the biopsy. What kind of lung cancer do they have? Uhhuh. That's the first thing. And then they can ask, have molecular testing. Have molecular tests been done or genetic tests been done?

Dr. Alice Shaw (05:27):

Does my lung cancer have any targets? There are many different ways you can ask, but the bottom line is, every patient should have this type of molecular testing done at diagnosis.

Annabelle Gurwitch (05:38):

Right. And, you know, when we think about this now, you know, you also, you're at Dana-Farber. Um, I get treatment at a major cancer center where these skis happen every day. But why that doesn't happen for some people, it might be, they might be in a rural area where there's so many new advances. Maybe, um, maybe the provider isn't a specialist in lung cancer. I mean, I think we, we, we wanna assume the best of everyone and every institution, but maybe they're just not prepared at this moment. So unfortunately it does fall to the patient. Uh, but a patient can ask absolutely. And it should be done. So one thing we're doing at Lung Cancer Foundation of America is we're gonna have a list of resources, uh, of who to turn to, to cover the cost. This testing can be expensive, and there are companies that do the testing that also help, uh, out with underwriting. And sometimes institutions can offer grants. So we just have to urge patients not to stop exactly. Before they get tested.

Dr. Alice Shaw (06:47):

Yes, there can be issues sometimes with coverage. And just as you said, there are sometimes the companies that are doing this genetic profiling. Have patient financial assistance programs and will help cover the cost of the testing. There are also, um, foundations who have been awesome. Right. And help patients get this testing done because it is critical.

Annabelle Gurwitch (07:06):

One day, I hope this isn't a problem, uh, but for now it's really important. And this is where, gosh, you have to become your own advocate as a patient. Absolutely. So, um, just before we go into the kinds of mutations, and you particularly work with patients who are ALK positive and ROS one, we'll talk about what those are. Uh, but what does that testing look like? Is that, is that a, is it strictly a, a biopsy, a tissue biopsy? Or can that testing be done through liquid biopsy? Can you tell us what a patient who's just coming into this should know?

Dr. Alice Shaw (07:42):

Yeah. So these genetic alterations can be identified in the tissue and sometimes in the blood. And so, at the time of diagnosis, if a patient has, uh, stage four or advanced lung cancer, actually it's become more and more common to do both tissue testing. So that's a biopsy of a site of cancer. But also in parallel to also submit a blood sample for liquid biopsy. Certainly at my institution, we do both in parallel, because sometimes a liquid biopsy can return a result very quickly. Sometimes within a week, we can identify a patient's driver, their oncogene, their activated oncogene in a week. Um, but liquid biopsies have some limitations. They don't always identify, um, a, a mutation even though it may be present in the tumor. And so that's why we also do tumor testing as well.

Annabelle Gurwitch (08:30):

Right. So we wanna encourage patients to, right now it seems like, uh, the most information consistently comes from a tissue biopsy. Exactly. And like for instance, um, a patient might find out that their liquid biopsy might not indicate what people might hear as like a tumor load. Is that, is that phrase meaning that just that that mutation isn't showing up in the blood. And that can be for different reasons, but so that's why they really need that tissue biopsy in

Dr. Alice Shaw (09:06):

Conjunction. And it's okay, it's okay to do a liquid biopsy, it's just that if it's negative or non-information Right. You can't stop there. You must have the tissue

Annabelle Gurwitch (09:14):

Tested. Right. What's amazing is how quickly you can get the results and also how many more things we can find out from liquid biopsy. And this is actually becoming one of the most important diagnostics. And even more important as it goes along, is we also know what this is, the way we see science move. Right. Uh, in, in a year or so, we may have less time than that. We may be getting even more information. Um, I wanna come back to that topic because as I understand it as well, um, understanding if it is showing up in the blood, how much of it is showing up there can help us understand where we're at in terms of the spread of cancer, right?

Dr. Alice Shaw (09:58):

Yes. We use it that way. Um, we also use it in the setting of a patient who may have been on a targeted therapy and now we start to see some signs that the cancer is coming back

Dr. Alice Shaw (10:08):

And so yes, a liquid biopsy can help confirm that. Now we have a higher load of the circulating tumor, DNA, but on top of that, we can get information about what could be driving the resistance, what are resistance mutations that can show up basically and cause relapses on targeted therapy. So liquid biopsies are becoming extremely

Annabelle Gurwitch (10:27):

Powerful for us. Wow. It's just amazing when you think about how far technology has come. And I think, um, one as a, as a, you know, person in treatment, sometimes when I, I hear the word hope, I, I don't know, it pisses me off. Like, I just like, what is hope? I, I I I think of Emily Dickinson's, uh, hope as a thing with feathers. And uh, of course that can be interpreted in many different ways. Uh, it can lift you up. But for me, when I heard the word hope when I was first diagnosed, it just made me angry. 'cause I felt like, oh, am I supposed to hope? Like, sort of like that made me, I heard it like, sort of like thoughts and prayers where it seemed like an ephemeral or something not to hang on to. But now when I think of the word hope, I think about, uh, advancements in science. And I Oh, hope is actually looking and seeing at the advances. And even since I was diagnosed five years ago, the advances are amazing. The choices for someone like me, uh, even at the start of therapy are different. And as we know, drugs are in the pipeline all the time. So, uh, I wanna talk about the two kinds of, um, mutated lung cancer that you work with, and specifically ROS one, because that's so rare. There's not a lot of people that specialize in that.

Dr. Alice Shaw (11:55):

Yeah. So ROS1 is, uh, pretty rare. We see these alterations in ROS1. They're specifically actually rearrangements, not mutations. So just to be clear about that, it kind of refers to a reshuffling in the chromosomes that have now activated ROS1. Um, we only see these rearrangements in one, maybe 2% of lung cancer patients. So pretty, pretty rare. I always tell my patients who have ROS one that they're rare and exceptional, um, which is true. Um, but they're really, it's important to identify, I mean, so important to identify. ROS1 because we have some amazing ROS one targeted therapies now that have really just been developed in the last roughly 15 years. And there's first and multiple next generation ROS one inhibitors that are really effective. And so we don't want any patient who is ROS one positive. Right. To lose out on that opportunity to access those targeted therapies.

Annabelle Gurwitch (12:50):

Well, so, so you, if you hear your ROS one positive, what that would be telling you is this is one of those biomarkers that has been identified. And, you know, you said something to me that you've had patients come to you for a second opinion who are ROS one patients who were originally with an oncologist who'd never seen a ROS one patient.

Dr. Alice Shaw (13:15):

Exactly.

Annabelle Gurwitch (13:16):

So that's why it's really important to get all the most up-to-date information. Exactly.

Dr. Alice Shaw (13:21):

Again, one to 2% of lung cancer patients is not that many. So it's very, very possible that, uh, especially a general oncologist who sees all different cancers, they may not ever run into a ROS one positive patient. Right. And the care is very, very specialized now. And so I do think that, um, you know, working together with folks experts, um, in the, in the field is really, really helpful for patients

Annabelle Gurwitch (13:43):

Every week on living with lung cancer, ask me anything. Podcasts, we explore questions that matter most to people living with lung cancer. We talk about new treatments, everyday challenges, new research, and we share the stories of patients and caregivers who are finding hope and strength. If you want these insights delivered straight to you, subscribe on any of the podcast platforms or go to lc a america.org. And if you know someone who could use some understanding or encouragement or both, share this program with them. And don't forget to subscribe now back to our conversation. So, um, for patients listening or watching this, so what this means specifically as I understand it, is that what we have to understand is that each of these mutated kinds, each of our EGFR, alk, these KRAS, this means you, you, a different treatment has to be done for each. Exactly. So what is the landscape, for someone with ROS one, what did that look like and what does it look like now and where's it going? It's a three part question. Yeah.

Dr. Alice Shaw (14:51):

And so, um, before we had any targeted therapies, patients with ros one, like other lung cancer patients really only had the option of chemotherapy. And we know that chemotherapy can help, but it's a relatively modest benefit. But fortunately, um, starting around 2010 or so, so now about 15 years ago, uh, we started testing the first generation ROS one inhibitor in, in the clinic and seeing some really remarkable results. And that really is what defined the field of ROS one positive lung cancer. Um, now those, that first drug worked really well, but not that well, that patients didn't eventually relapse and they typically relapsed, um, within the first one to two years. And so that really stimulated more research to develop even better ROS one inhibitors. So now we have next generation ROS

Annabelle Gurwitch (15:38):

One. And when someone hears an inhibitor, just to be, just to be really clear, uh, that's, that's a good thing, right? That's an, that's the thing that inhibitor meaning it stops, it's going to inhibit

Dr. Alice Shaw (15:50):

Or block the activated ROS one.

Annabelle Gurwitch (15:53):

Right? Right.

Dr. Alice Shaw (15:54):

Um, so we can call that inhibitor, we can say TKI, uh, we can call it just targeted therapy. But we do have all of these targeted therapies now specifically focused on ROS one, and they're, and they're really good even compared to the first generation ROS one drug that we have. Um, so what's the difference

Annabelle Gurwitch (16:10):

Between what existed in the past and what exists now?

Dr. Alice Shaw (16:15):

Yeah. Well, I think from all of our work around the early generation ROS one inhibitors, we are really able to understand how they work and then why they stop working. So why do patients eventually develop resistance to these drugs? And we learned that there are many different reasons why, but a common type of mechanism or resistance was that the ROS one gene itself would try to mutate again, so that those early generation drugs would no longer work. So cancers do the same thing. They outsmart the drugs that they may be exposed to. Um, but now based on all that information and why that happens, we have much, much more potent, TKIs targeted therapies, um, in the clinic targeting ROS one. These have been designed to be really potent, meaning it really shuts down this activated oncogene really, really well. They've been really optimized to try and prevent even these resistance mutations from forming within ROS one.

Annabelle Gurwitch (17:11):

So when you say, okay, Dr. Cha, when you say really potent, that makes me a little nervous. Um, so what kind of, uh, side effects, uh, do, can a person, uh, in treatment expect? Is it, are we saying potent, like it's targeted just to that cancer? So what are the, what, what are, what is the trade off?

Dr. Alice Shaw (17:35):

Yes. So that is an excellent question. Um, with ROS one, fortunately we are learning with all of these new ROS one inhibitors that if you can hit ROS one itself really hard, that's actually very well tolerated by patients, it does not come with a lot of side effects. Issue though is that some of the ROS one inhibitors or TKIs, um, aren't as selective for ROS one and may actually block other important proteins. And that's what then causes some of the side effects. Oh,

Annabelle Gurwitch (18:04):

Oh, okay.

Dr. Alice Shaw (18:04):

So the newer ROS one drugs are both really potent. They inhibit or block the ROS one well, and on top of that, they're very clean for just targeting ROS one.

Annabelle Gurwitch (18:16):

So I, I think as a patient, when I, when I hear that, I wanna make sure I have the, like, the right wave of understanding that. So that's where we look, that's what you're looking for when you're looking for improvements or what people might call next generation drugs. Right, exactly. It is that it's even more potent to the cancer and less

Dr. Alice Shaw (18:40):

And more and more selective for cancer.

Annabelle Gurwitch (18:43):

Right.

Dr. Alice Shaw (18:43):

That way you hopefully then decrease or prevent any side effects.

Annabelle Gurwitch (18:48):

Right. And that, that's also the advantage to something like, um, traditional chemotherapy because that affected your whole body. Exactly. Right. So this is when they put the target in the target there. Exactly. That's right. Okay.

Dr. Alice Shaw (19:02):

The other thing that, um, the newer ROS one drugs, um, have done is that they actually have been optimized to penetrate into the brain because patients with lung cancer in general, but I would say also ROS one, um, they do have a risk of having the cancer spread to the brain and now causing brain metastases, which you can imagine can be very, very difficult for patients.

Annabelle Gurwitch (19:24):

Yes. I've had, I've had a number of patient friends as, as in the patient community, you know, people call them, you know, brain mets, and I didn't know what that meant, honestly, for Omar, what are they talking about? And that's brain metastasis.

Dr. Alice Shaw (19:36):

Exactly. Exactly. And so these new ROS one drugs though penetrate, have been designed to penetrate into the brain

Dr. Alice Shaw (19:44):

Um, and actually not only treat brain metastases in case they're there, but also potentially prevent brain metastases from forming. That is huge. That is, uh, really, I would say the incredibly important, um, aspect of these new drugs is that you're treating the cancer well, not just in the body, but also in the brain.

Annabelle Gurwitch (20:04):

So you're treating the cancer well, not only in the body and the brain, and you are potentially shrinking tumors, but you're also adding a layer of protection. Exactly.

Dr. Alice Shaw (20:15):

You're protecting the brain from this dissemination of the cancer.

Annabelle Gurwitch (20:20):

So are these drugs in trial? Like when I, if I'm listening to this and I'm a ROS one person, I'd be like, okay. How, when, yeah. What's the timeline for me? Well, I

Dr. Alice Shaw (20:30):

Mean, again, space is very complicated. There are actually four Ross one targeted therapies approved in this country.

Dr. Alice Shaw (20:38):

And some of them are the newer generation ones. Um, there are others in development. There's one in development that's probably the latest one in mm-hmm <affirmative>. In clinical development right now that has been even, even better optimized in terms of what we talked about earlier, potency. Selectivity, brain penetration. And that one Annabelle, I'm particularly excited about because, um, because of the selectivity, meaning that it's only hitting ROS one. Mm-hmm

Dr. Alice Shaw (21:03):

It's selective for cancer. It seems to have a much better safety profile. So of course, side effects are, uh, really important, especially when patients stay on drugs potentially for years. And so we really need drugs that have the cleanest side effect profile. Right. And so this latest ROS one inhibitor does have a very, very safe, um, side effect profile. And that's what makes me very

Annabelle Gurwitch (21:25):

Excited about it. And that's been in trials, like just how, how, how does that, how does that work? And typically, how long does it take for that to get to people? Mm-hmm. Like, uh,

Dr. Alice Shaw (21:36):

Well, so yes, it's been in a clinic, this particular one that we're talking about has been in clinical trials for about four years or so mm-hmm

Dr. Alice Shaw (21:43):

Um, there is a lot of data that's now been generated. And, uh, I think the data is very compelling. It's been presented in, in conferences, for example. And I think there's a real need, right. To have a really very active drug that doesn't have very many side effects. And so our hope is that, um, the data would be strong enough to support, hopefully eventually approval. So becoming a standard drug, it's not a standard of care drug yet, but our hope is that it would be based on the data.

Annabelle Gurwitch (22:09):

And is there a timeframe that typically takes place?

Dr. Alice Shaw (22:13):

Well, it always varies depending on the drug. Um, but we have, with these targeted therapies, EGFR, ALK and Ross targeted therapies, we've been able to move really quickly. And so in some cases, we've moved from the very first in human phase one clinical trial to FDA approval in three and a half, four years. I mean, it can be very fast. Um, you know, depending of course on the data, how active is it? How safe is it?

Annabelle Gurwitch (22:39):

Right. Okay. So I'm so glad you brought this up because, uh, uh, I think as a, as a person in treatment, uh, we hear about drug trials and you hear about that with both longing, like, oh, I wanna be involved in a drug trial and trepidation of what is what. So can you talk about the drug trial process? And, and it's such, it's so important in the development of drugs, but we don't always know how to participate in it

Dr. Alice Shaw (23:10):

Well, so clinical trials are absolutely key. That is the only way we can bring new drugs to patients. Uh, we have to test them initially to make sure that there's, and on humans, yeah. There's nothing else. There's no other way to get a drug to an approved standard of care until we've done all of the testing in patients. Right. By the time a drug gets to the clinic, there has been extensive testing done pre-clinically, so in cell lines and animal models. But we have to be able to test patients. To establish that a drug is safe, that the drug is active, um, and, and determine what dose and how to give it. All of those things do have to be tested initially in order to have a standard of care drug

Dr. Alice Shaw (23:53):

And so that process starts with a phase one trial. That's the first time a drug enters the clinic for patients. And that's where, that's a really key point because it's a brand new drug. We're just learning about it. That's where we determine whether or not the drug maybe has legs. Right. Right. Is it safe enough?

Annabelle Gurwitch (24:09):

Do you, uh, find that your patients come to you and ask you about trials? Or can we, can we encourage patients to find, I mean, let's say your oncologist, let's say you're with a provider who's not a specialist, which seems like it would not be great if you have Ross one because you really need to be with a specialist. But how do people, um, hear about trials if they're not involved in the world? Or what do you suggest? Yeah, it might be a tough question to ask.

Dr. Alice Shaw (24:38):

I mean, you're right. Usually you learn that information from your oncologist mm-hmm <affirmative>. But you're absolutely right. That doesn't always happen. In which case, what I've seen patients do is certainly that patients are really savvy and they can go on the internet and research these themselves. That's pretty hard to do. But a lot of patients do that patients can find through various advocacy groups. Um, communities, the Ross Wonders are a great example. Um, they're incredible patient advocates, patients themselves. They are resources and they know everything about,

Annabelle Gurwitch (25:07):

I know, you know, a lot of the patient groups, we do keep track of, uh, studies and trials, but I just wanna, I guess I wanna affirm that it's okay to ask your doctor about, uh, being in a trial. You know, it is one of these funny things, even as I'm saying this, I feel like, God, it really sounds silly for me to say this, but I

realize, oh, you know, asking about that sometimes feels like asking about a second opinion. Um, and this is, I think, something to do with the old paradigm of, I do what my doctor says to do, and I have a voice in my treatment to say, okay, if I ask about a trial, am I saying, uh, I don't trust your what you're doing? No. Isn't that, it's kind of, that's, no, I think it sounds kind of crazy, but I think this is where we go because we feel so vulnerable as patients. I

Dr. Alice Shaw (26:04):

I would say the mindset should be that, um, if, for example, if you have one of these oncogenic drivers, like Ross one that, um, the way you could think about it is, is that the therapeutic landscape, meaning all the different drugs there, right? The pace of that drug development is so rapid, and the drug development starts in clinical trials, and there's just no way you can access the newest drugs that are likely to have even more effective viewer side effects unless you actually know about the clinical trials. That's how I view it, that there's just no, we're constantly making progress. And I would think most patients want to be kind of at that leading edge.

Annabelle Gurwitch (26:43):

So if you're listening to this and you've got this diagnosis and your, uh, doctor hasn't mentioned trials, but how, how do you advocate for that? Do you need to switch doctors or, I mean, what is, what is, what is the process?

Dr. Alice Shaw (27:01):

Not necessarily. I would say the first thing is to ask your doctor, of course. About clinical trials. Are there any clinical trials for my, for example, ROS one, positive lung cancer.

Annabelle Gurwitch (27:11):

Right.

Dr. Alice Shaw (27:11):

Um, and they may say, no, we don't have any here. And then you can ask them, well, how about elsewhere? Do you know of any clinical trials? Or have you seen any emerging clinical trial data? And they may not know. And, and if they don't know, that's fine. Um, you can ask them for some sort of resources. I think a lot of patients though, especially if they have EGFR, alk or Ross one, they do have some resources that they can access themselves online. Um, and I usually do recommend, for example, if a Ross one patient really wants to connect with a community of, I would say, other patients who are themselves, ROS one experts, they can go to the Ross Wonders.

Annabelle Gurwitch (27:47):

Right.

Dr. Alice Shaw (27:47):

Um, and that's one way to find

Annabelle Gurwitch (27:49):

Yeah. I, I think it, I think we, we can't assume people have those connections because I know I didn't at first. So one thing we can do in the community right, is to work to make sure people find out where

those communities are and to, to attract, to help attract new patients. Um, I think it's really interesting, uh, what you just said though. I think if, if I heard that, uh, a particular institution didn't have a trial there, um, I'm not sure, I'm a little embarrassed to admit this. I'm not sure I would know how I would think, well, can I, can I still receive care from my oncologist, but be in a trial with another institution? I think I know the answer, but can you address that? 'cause am I just the only person who would worry about that or just actually worried? It

Dr. Alice Shaw (28:45):

Happens all the time. Okay. Um, where patients are somewhere in a different part of the country where they don't have a clinical trial for Alka ROS one for example. And so they travel up to Boston, for example, to participate in a trial. And we get them going on their new targeted therapy as part of a trial. However, they live far away from us. And so we do actually work with their local oncologist. So they stay with their local oncologist, and they now have an extension of their team. Up here in Boston. And so I do think you don't necessarily have to say, oh, I'm gonna lose my whole team that I've been working with, um, because I'm participating in a trial. Many of my patients stay with their team as

Annabelle Gurwitch (29:23):

Well. Right. I, that's a really important point, I think, for people to know because, uh, let's say you really love your provider or you live somewhere and it's just not, you know, financially, uh, possible for you to relocate. There is a way you can stay with your provider and participate in trials. And also I think it's important to mention that, uh, we're gonna have a link up at, um, LCFA that also, um, has a list of organizations that help you with funding. Well, I think this, we, we do know that this is one of the reasons why, I mean, I know that, uh, a lot of, uh, testing that's being done now, efforts are being made to include more kinds of people in trials. But if there is an expense, uh, to do with, uh, participating in the trial, which there often are, there are organizations that can help underwrite that. Absolutely. So unfortunately, we have to be, uh, more proactive than it would be great if everything was done for us. And I don't say that lightly. I mean, I think we know there are healthcare systems that provide more resources in this way, but this is what we have to do as patients, because what are we talking about the differences? If you don't get these targeted drugs, we're talking about life and death.

Dr. Alice Shaw (30:48):

Yeah. I mean, these targeted drugs are absolutely critical to every patient for whom that targeted therapy has been developed. Right. Um, you know, I would say, just to clarify that if a patient participates in a clinical trial that care, the care they're getting around, the trial is done at that site. But you can imagine that things happen outside the trial. Yes. You go home, you're not feeling

Annabelle Gurwitch (31:08):

Great. Right.

Dr. Alice Shaw (31:09):

We need to be involved, we still need patients to be involved with their local teams. Uh, I just wanna make sure that was clear.

Annabelle Gurwitch (31:14):

Yes. And also, I think also something I just realized should be clear too, is that, uh, let's say you participate in the trial and then you're not participating. You, you can go back. Absolutely. Right. And we do that all the time.

Dr. Alice Shaw (31:25):

And then you can even come back again for another clinical trial. So Right,

Annabelle Gurwitch (31:29):

Right. It's, and it's okay. I think we should let patients, people in treatment or caregivers or any of these stakeholders know it's okay to, to first of all, ask for a second opinion. It's okay to ask about trials. It's okay to participate in a trial, come back to a provider, a, a good, a good, um, center and provider isn't, it's not like a bad breakup. No, not at all. Where, like, you should be, you're gonna get ghosted. Not at all. No. Yeah. If that's, now that's a problem. If that was happening, that would be a problem. But we have to, we have to overcome, I think, some fear of saying or doing the wrong thing and really empower ourselves.

Dr. Alice Shaw (32:12):

And I would say that there are a number of oncologists who aren't at these big centers. They're in the community. They wanna learn to, they really wanna help their patients find trials. They reach out to me directly about trials, so they can definitely help. Um, as

Annabelle Gurwitch (32:23):

Well, uh, this, you know, our conversation just reminds me about how, um, just how, how great the lung cancer community is and how much I have learned. And also just appreciate this kind of conversation. And I just wanna encourage people who are watching and listening to, uh, to have these conversations. And, um, I, I really appreciate your time, Dr. Shaw. Thank you, Annabel. I know you have to get back to patience. I do. I do.

Dr. Alice Shaw (32:53):

This has been great. Thank you so much for having me. Oh, thank you.

Annabelle Gurwitch (32:57):

Thanks for listening to Living with Lung Cancer: Ask me anything. I'm Annabelle Gurwitch, which if today's conversation helped you follow, subscribe, share this episode with someone who might need it together. We can change the way we talk about lung cancer. And if there's a lung cancer related topic you want us to explore, let us know in the comments. Find out more at lcamerica.org or you can find me on the socials or at my website, annabellegurwitch.com.