14 Years Strong: Lysa Buonanno on Clinical Trials, ROS1, and Living Long-Term with Lung Cancer

Lysa Buonanno (00:00):

It's amazing how fast really that it's changing right now and the momentum of now that they've ... The more they learn, I feel like it just opens so many more doors.

Annabelle Gurwitch (00:11):

Living With Lung Cancer: Ask Me Anything. Real conversations with people living with lung cancer. Learn from personal journeys and expert insights. Subscribe and never miss an episode. Hi, I'm Annabelle Gerwich and I am your host for this episode of Living with Lung Cancer: Ask Me Anything sponsored by Lung Cancer Foundation of America. And on this show, what we do is we have the kind of conversations that I had hoped I could have and I would have benefited from when I was diagnosed five years ago in the spring of 2020. I'm here with Lysa Bounanno, who is a patient advocate, an amazing person, a grandmother, and happens to be the very first person I met who also had lung cancer and has taught me so much and we're going to be having a conversation about a number of topics. We want to talk about what it's like to live in long-term therapy to go from line to line.

(01:22):

My experience is only on one line of therapy. Lisa has really run the gamut. We're going to talk about clinical trials, what it's like to participate in them, the importance of doing that. As I always say, it's a public service. You're not only being in a trial for your own health, this is something we're doing to help all the millions of people with lung cancer. We're going to talk about how our identity changes when we've been diagnosed. Lisa, I'm so happy to see you.

Lysa Buonanno (01:55):

I'm so glad to be here and so great to see you again.

Annabelle Gurwitch (01:58):

Let's give a little bit of this story of first of all how we met. We were introduced through Lung Cancer Foundation of America.

Lysa Buonanno (02:10):

Yes. We were doing a charity event to raise awareness and donor funding for lung cancer research.

Annabelle Gurwitch (02:18):

Which we know is underfunded.

Lysa Buonanno (02:20):

Absolutely. And it was a great event. You were our amazing host and I got to cook and go head to head with one of our researchers and we had an amazing restaurant that was lent to us for that purpose and it was just a really great event and it was awesome to get to meet you.

Annabelle Gurwitch (02:40):

We met the night before the event. The minute I saw you and I met your mother, I burst into tears. I just had no idea what it could look like to be living in this time of precision medication and you were so warm and welcoming to this community and I think we're really lucky. We were brought together by the Lung Cancer Foundation of America and the support of that community as well as the many communities that we interface with is really unparalleled. And some of that I think is because people didn't survive lung cancer. We really need each other.

Lysa Buonanno (03:27):

Most definitely. And you're not alone. So many people I think don't reach out for whatever reason or don't have a lot of hope in the beginning of their diagnosis and they do walk those days alone, especially in the beginning when everything is very overwhelming, very scary.

Annabelle Gurwitch (03:48):

Yes.

Lysa Buonanno (03:49):

You don't even know where to reach sometimes. And I think for me personally, just having those connections with other survivors, people that truly have walked in your shoes and you don't have to explain things, they just understand it. And it's a type of support that no matter how great your family and support system is,

Annabelle Gurwitch (04:11):

They

(04:12):

Just can't get it. Yeah. I think that that is something ... I'm on this book tour. My book, The End of My Life is Killing Me has come out. And this has been this really profound experience. When I do events, people want to tell me their stories. And I meet a lot of people in treatment for lots of different things. One of my goals with this book and this podcast is to encourage people to get support and exactly what you just said. I think there's something, whatever kind of issues you are facing as a person besides lung cancer and stage four lung cancer, which we were both diagnosed with.

(04:55):

If you are facing something that doesn't also have a beginning, middle and an end that is distinct, but a long-term care, you have to have a long game strategy. When we're looking at this long-term, it's really important to have a lot of people in your corner and I think there's a feeling that people have like, "Oh, I don't need it. I don't want to be a burden." That's one feeling. I can do this. I'm a cancer warrior and you know me, I call myself a cancer slacker. And the reason I do that is because I just want to give people permission to not feel like they have to be strong all the time. Do you feel like ... Well, you are ... I feel like if anyone is a cancer warrior. You

Lysa Buonanno (05:44):

Cancer warrior analogy.

Annabelle Gurwitch (05:46):

And I love you for that.

Lysa Buonanno (05:47):

I know some people love it. Some people hate it, but I can totally resonate with it. I think because from the beginning, I just felt like it was like this momentous thing I'm trying to partially overcome even though I knew it wasn't curable, but just to overcome the little things, the physical issues I was going through, recovering from multiple surgeries I had to really break it down into kind of conquering smaller things, living more day to day than looking at that long term picture because I think it's really hard to do when someone tells you

Annabelle Gurwitch (06:30):

Have a

Lysa Buonanno (06:30):

Terminal illness.

Annabelle Gurwitch (06:31):

Yes. The first

Lysa Buonanno (06:33):

Thought is I'm not going to have that long term future.

Annabelle Gurwitch (06:36):

Right. I think that is one of the things that I address in my book and always when I talk, I talk about small joys and making smaller increments of time destination points. Sometimes it's an hour to an hourly thing. There's something profoundly interesting that happens when someone isn't involved in your day to day life. So they have a kind of detachment and I can call you or you can call me or Laura Book can text me some of our people in our community and we're in some ways a very loose community but a tight community. Laura Book, who's an EGFR resistor, fellow of mine, if she texts me, "I've got a scan today." I think that because I'm not in her daily life, I can have a distance to ... It doesn't upset me emotionally in this. I mean, I'm upset emotionally if Laura is ... I have my Laura, my Lysa.

(07:39):

We have all of our friends in the community, but I'm able to be there for her without the kind of emotional impact it is if I email my sister, my very close friends, oh, I know it causes them suffering and they work really hard on it too. But you know what I mean? It's just a different kind of ability we can do for each other that, I want to say ability, a kind of connection that is a support and I urge people to

Lysa Buonanno (08:14):

Each other. I definitely feel like I take care of everybody in my family. I feel like I'm the strong one. I'm the one people come to handle situations when things are not going well. I feel like I'm very logical. My brain just wants to fix things. I'm the go- to person. So I think not that I have a hard time asking for help, but I have a hard time feeling like I know this is going to crush them. I know my mom is already going through enough. I know my husband doesn't want to hear me say one more time, but when I die, because I've accepted this and I've already got this plan and I'm already trying to take care of him when I'm gone. Yes.

Annabelle Gurwitch (09:07):

Many of us have done this. He doesn't want to hear me

Lysa Buonanno (09:09):

Say

Annabelle Gurwitch (09:09):

That anymore. No, and it's understandable. And I think to make our peace with all these different aspects, like we understand the effect it has. My sister, when I was celebrating my first birthday a year into treatment, I had not dead just resting printed on the cake and it really upset her. She's like, "You think it's funny, but people who love you. " So it's just hard. They just haven't

Lysa Buonanno (09:39):

Quite accepted it or don't want to think of that reality,

Annabelle Gurwitch (09:43):

Right? Right. And so we share things we can't share with other people and I do want to mention for anyone listening or watching this YouTube that you can participate in our support groups, you can go to the websites and you can do it anonymously Whatever works for you and I think we are there for others and it's this amazing relief to talk to people. So when I met you, I burst into tears and your mom hugged me and I immediately was like, "Okay, Lysa, tell me everything. What do you do? " I was like, I just had to like suck the knowledge from you. So now to share this knowledge with everyone who's listening, you and I have had many of the same experiences, but you've also had different experiences in this world. I have been on the same line of treatment for five years, targeted therapy.

(10:43):

When you were diagnosed, that wasn't an option for you. No. And I wanted you to talk a little bit about when we see you, we are looking at you who've been in treatment for, I always forget how many years, because we've known each other for a long time. 14

Lysa Buonanno (11:01):

And a half year.

Annabelle Gurwitch (11:02):

14 and a half years. Yes. So just saying that number out loud and this is extraordinary, it couldn't have happened in the past. The technology wasn't there and why don't you tell us about some of the lines or all of the lines of treatment that you have been on?

Lysa Buonanno (11:26):

Well, like you said, I mean, just to say even when you were first diagnosed, did you even think I could be on this treatment for five years? No, absolutely. This can help extend my life

Annabelle Gurwitch (11:38):

Five

Lysa Buonanno (11:38):

Years.

Annabelle Gurwitch (11:39):

Well, the survival, five year survival rate was still being calculated around 5%, which is terrible at math, does not sound good. Pretty minuscule. Yeah. It's very small. Now if you respond to the medications and treatments, it's hovering maybe 27%, which is extraordinary. Huge. Still very serious and intense and deadly disease as we know, which is why supporting science is really important. But okay, here you are being diagnosed 14 years ago.

Lysa Buonanno (12:14):

Biomarker testing was very new, was definitely not standard of care.

Annabelle Gurwitch (12:19):

Yes.

Lysa Buonanno (12:20):

I did not know about it as a patient. Why would you?

Annabelle Gurwitch (12:24):

Right.

Lysa Buonanno (12:26):

My doctor didn't mention it. I had biopsies. Yes, you have adenocarcinoma. Basically, I felt like they're opening a book. This is what we do. So I had standard systemic chemotherapy. I had radiation to my spine to treat some tumors that I had had surgery on. I had a lot of back issues

Annabelle Gurwitch (12:50):

Still

Lysa Buonanno (12:51):

Because of their location. So those needed to be addressed right away. I did chemo, which I have to say I was on three different drugs and one of the drugs I was on is rarely used anymore, but it did a great job, but it was also quite miserable.

(13:10):

I remember my mom sitting there on the couch, she would just watch me doze off and on all day with my dogs being nauseous because they have also gotten better nausea meds, which thank God, because there were times that you nap through, you're supposed to have a dose every four to six hours and you're sleeping for a few hours and then you just wake up sick. So it was pretty bad. I'd lost a lot of weight. I was very frail, didn't want to eat anything. And I remember my mom, just this look on her face and staring at me and I was like, "Mom, I'm not dying." And she was like, "I don't know that, Lysa”

Lysa Buonanno (13:47):

And I just thought if I could just get through this, I developed a mantra that I would just repeat over and over, "This is temporary. I'm not going to feel like this forever. One way or another, things are going to get better." But it was very effective for me. I mean, I had a very large tumor in my lungs along with lymph nodes all over my spine and it worked very well, but I learned so much in the first year and I learned that from other patients.

Annabelle Gurwitch (14:23):

It wasn't

Lysa Buonanno (14:23):

My doctor.

Annabelle Gurwitch (14:24):

Yes, me too. So I'm going to say in our commonality of experience, even if you start on targeted therapies, there is a wide spectrum and it's really important to know there's a wide spectrum of side effects and toxicities. We who are on targeted therapies, we feel so grateful that sometimes many times we don't want to talk about the toxicities because we don't want our doctors to think we're jerks. We

Lysa Buonanno (15:00):

Don't want to take away-

Annabelle Gurwitch (15:02):

Take away from the fantastic opportunity we have at lengthening the time and one of the things we're all doing right now because there's not a cure, we are trying to stay alive, but we are also trying to have a quality of life that makes our life worthwhile and worth living till we can get the better treatments. And so that was a really profoundly unexplored idea for me. Some doctors, like I know Dr. Alice Shaw does this at Harvard.

Lysa Buonanno (15:38):

She's

Annabelle Gurwitch (15:38):

Amazing. And there are many doctors who do this now. I mean, first of all, care is evolving. So Alice told me, she tells people at the very beginning that we will try different doses to see what is tolerable. I didn't know that. So I spent three months basically going from being sleeping to using the bathroom constantly. Sometimes both at the same time I would fall asleep in the bathroom. It was not what I would call living. 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 lcfamerica.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.

(16:52):

After you do these initial rounds of chemo radiation and you have had surgery as well, what came next?

Lysa Buonanno (17:00):

It was through an online patient group that people kept talking about biomarker testing and there are many things that kind of lined up that it was very likely. I would have biomarker testing. I was a younger woman. I was diagnosed at 40 years old. I had no other known risk factors. I didn't work with certain chemicals. There was no known radon in my area. I was not a smoker. So there was nothing we could point to.

Annabelle Gurwitch (17:34):

Do you want to mention the mutation that you tested positive for?

Lysa Buonanno (17:37):

Yes. So my cancer is positive for ROS1

Annabelle Gurwitch (17:40):

Biomarker. You're a Ross wonder.

Lysa Buonanno (17:42):

I'm a Ross Wonder.

Annabelle Gurwitch (17:43):

And I'm an EGFR resistor.

Lysa Buonanno (17:45):

You are. See, you are a resistor. So I think they really urged me and they also kept saying, "You should get a second opinion," which I know is something that is really important that we're going to talk about too. But I think

(18:04):

When I first brought it to my doctor, she was like, "You're having a great response. We'll do that kind of down the line when the time comes." That pacified me for a short time until I had progression. Don't fix it. Right. Let's just keep doing what we're doing. We did drop the very toxic drug, so I was just on two other drugs that were much easier for me to tolerate. So I just stay with the course. Let's do this. And then I had progression at that point we did try to do two needle biopsies. I came back conclusive. Then there's a lot of dead tissue is a very hard access or place to access

(18:46):

And she just wanted to do another chemotherapy and everything in me was just screaming to run. No, I don't want to do chemo again. I need to know. So I switched doctors and my very first appointment with this man, he was in research for many years in Chicago. This was in Las Vegas. He mostly saw prostate patients, and was actually responsible for bringing a lot of trial drugs to Las Vegas. So I was his only younger lung cancer patient and he was like, "You know what? I'm going to call up a buddy real quick." He called up a thoracic surgeon while we were in the office and said, "I have a young woman in here. She's a great candidate for surgery. I think we need to do this because we need to test for a tumor. We need to know the makeup of what's going on. " So I had the right lower lobe and my lung removed for the sole purpose of biomarker testing.

(19:46):

Because how important get

Annabelle Gurwitch (19:48):

A biopsy, wow.

Lysa Buonanno (19:50):

That's how important he thought this was. We have to know and I'm so thankful for him. He was my oncologist for nine years and he actually called me back. It took about four weeks to get results back for next generation sequencing and it was awful waiting. I did one round of chemo in between. He called me at 10:00 PM and he's like, by then I knew what some of the biomarkers were through the other patient group. I knew that EGFR, ALK, ROS1, I knew they had drugs to treat them. I knew there were oral medications, much more tolerable. And you found

Annabelle Gurwitch (20:26):

This all out through patient support groups. So that's also affirm for people listening that it's not only the emotional support, but we share information and again, we're not saying there's any ill will or desire to keep informations from patients, but also some people are in places particularly in rural underserved areas where they don't have access to a cancer center. So if you're going to a community provider who's not a specialist in lung cancer, it's hard enough for the thoracic community to keep up with all the new advances. They may not know. We want to give everyone the benefit of the doubt. And I feel for these community providers who are dealing, they're understaffed, they've got so many different kinds of cancers, our patient groups are here for you.

Lysa Buonanno (21:26):

Yes. I mean, they might see six different cancers that day. They can't know everything. They can't know the top of the line drugs or trials for every cancer. Right.

Annabelle Gurwitch (21:37):

I want to mention that this is how important it was to not ... We couldn't get a biopsy. They needed to remove part of your lung and this makes all the difference, right? Yes. So you hear your ROS1, did you just ...

Lysa Buonanno (21:53):

Yeah, he was very excited. He was like, "You're ROS1 positive." And I already knew there was a drug for that. So I was like, "Oh, thank you. " Oh my gosh. So excited. But like you said, they have their own list of side effects,

Annabelle Gurwitch (22:07):

Right? Yes.

Lysa Buonanno (22:08):

So each little pill I had divided, I did the math and it was about $200 a pill, which I had to take twice a day. Every single one of those pills made me throw up after taking them within an hour and all I kept thinking is, "There goes my pink little pill. There's my cure. There goes $200." And we tried everything, different nausea meds and steroids and eventually, thankfully my body just adapted to it, but still a lot of them do have GI effects. So I lived off Imodium for quite a

Annabelle Gurwitch (22:43):

While. Many of us are tithing our income to Modium. You know what's so funny and this is the kind of thing too, let's face it. We are talking about some topics that are in some sense taboo in social conversation, right? If

Lysa Buonanno (23:00):

You get a group of cancer patients together and you don't talk about poop, there's something wrong.

Annabelle Gurwitch (23:04):

Something is wrong with me. I

Lysa Buonanno (23:05):

Know. It always comes up because

Annabelle Gurwitch (23:07):

We're always

Lysa Buonanno (23:07):

Dealing

Annabelle Gurwitch (23:07):

With

Lysa Buonanno (23:08):

It one way or the other.

Annabelle Gurwitch (23:09):

And this is another reason why support groups are really important because it's like these are issues that are ... And we get it and that is another life changing event. So here you are, now you're on this ROS1, this was your first biomarker line treatment.

Lysa Buonanno (23:29):

Yeah, my first targeted therapy was crizotinib. Again, similar I think to Tagrisso is the average duration 18, 19 months. I know you had mentioned this when you got close to your timeline, that you were very nervous. That is my time ticking on this drug, is it going to stop any time now? Yeah. And I think that's hard to get out of your head once you kind of get near that timeframe, but I was just very grateful obviously for every day that extended my life, allowed me to be here with my family, allowed me to be functional.

Annabelle Gurwitch (24:16):

For someone like me, maybe you and maybe others listening, I want to know I cannot afford to not look at the reality of the situation because it was so devastating to me to get this diagnosis. I don't want to experience that kind of shock again. I prepare myself. Now you could look at the pluses of minuses of that. Now if that starts to dominate my day, that's a problem. However, I do live in a way that has ... I live with the knowledge this is going to happen so that when the day comes that my scans show progression that I'm not going to be destroyed in the same way. I can't afford that. I was so destroyed at the beginning of the first diagnosis.

Lysa Buonanno (25:12):

I have to say as someone who has had progression a few times and thought I was very well prepared

Annabelle Gurwitch (25:20):

To

Lysa Buonanno (25:20):

Hear-

Annabelle Gurwitch (25:21):

Well

Lysa Buonanno (25:21):

Preparing. It's back.

Annabelle Gurwitch (25:23):

Yeah.

Lysa Buonanno (25:24):

I don't know if you can.

Annabelle Gurwitch (25:26):

Well, at least it's in the realm of possibilities, right? Yes. I mean- And

Lysa Buonanno (25:31):

I think too, we're much more knowledgeable overall on what comes next. We already know I think most of us, we already know what plan B is and maybe C or D, at least potential options, right?

Annabelle Gurwitch (25:47):

Potentially. Of course then things change because we know every year and you and I follow this very closely and I just want to say also if you're listening and you don't have the time or the bandwidth to follow every trial, to feel like you know everything going on, first of all, it's really hard to do that. Yes. Let other people do it for you and then read about it. It can be overwhelming and also, I just want to mention too, I have friends who've been in long-term advocacy and lung cancer who also step back for a minute and say, "I can't do this right now. It's too much for my life. That's okay too."

Lysa Buonanno (26:28):

I've definitely had to take time when I had progression, times where I was so excited that people wanted to hear my story and people would talk about lung cancer. I said yes to everybody. I have done- I've done

Annabelle Gurwitch (26:42):

That.

Lysa Buonanno (26:44):

I have been on four flights across the country in the same month because they just lined up that way and it got to a point where I was like, "Okay, is it sustainable?" You can't say yes to everything. You still have to have a life. We have limited energy some days and so I think if you number one, regarding any type of advocacy, right? Speaking out there's so many different forms of that and I think it has to start with self advocacy and for me I suggest I also mentor newly diagnosed patients and I always recommend to them, I know it's scary and knowledge is power doesn't always necessarily work for everyone, but I encourage you to learn at least a little bit about your own disease. I hate when I ask someone and I'm like, "Oh, that's awesome. You're already taking a pill so we know they've had biomarker testing, they're on a targeted therapy, what drug are you taking?" "Oh, I'm not really sure.

(27:57):

"You have to know a little bit about your disease to advocate for yourself and maybe not you if that's too much, right? You can ask this.

Annabelle Gurwitch (28:07):

Yes.

Lysa Buonanno (28:07):

You have your

Annabelle Gurwitch (28:08):

Spouse. Or a patient mentor who can help you to also share that information. It is important and I do want to say too, I was a C minus science student. I am terrified of anything that sounds sciencey. I have been able to learn a functional amount. If I can do it, anyone can do it. I am absolutely convinced. After the targeted therapy, that targeted therapy stopped working, what was the next and how long did you get on that targeted therapy?

Lysa Buonanno (28:45):

I was on it for five years before I started having progression.

Annabelle Gurwitch (28:49):

What a honeymoon.

Lysa Buonanno (28:51):

Amazing, right? Yeah. And I think even with having those side effects, you just learn how to manage them, right? Like I was still traveling, I was still doing things and ran around with Imodium in my pocket.

Annabelle Gurwitch (29:06):

Okay. But let's stop for a second here. We learn how to manage them, but this is a related issue, but I think it's a good moment to bring it up. Many of us, I don't want to say most of us, I think it's really all of us except for like three people out there. We are managing side effects. Even if it doesn't look like it though, our lives are affected, our identities take a hit and I think it might be just a good moment to talk about how most of us don't work at the same level we worked at. We have found that that is hard. Everyone I meet in treatment all over the world, many of us have changed jobs. We have changed responsibilities. I I wondered if you could talk a little bit about that.

Lysa Buonanno (30:02):

I had to quit working and I know a lot of people are in that position because of the location in my tumors on my spine. I've had two surgeries on my spine. It's caused a lot of issues. I have back pain every day. I try to push through a lot of times because I want to enjoy my life. I enjoy being active. I enjoy working out. I enjoy walking. I ride my bike, but there are days that I'm like, no, not today. I will rearrange my calendar because I just can't push through. And I've had treatments. I do see an amazing pain management doctor that's tried to help. I've had injections and different procedures done to help eliminate that pain, but it doesn't go away.

Annabelle Gurwitch (30:54):

And what did you do next?

Lysa Buonanno (30:58):

I didn't work for a couple years till I kind of wrapped my head over everything around what was going on. And then because I went on that targeted therapy, I felt good enough

Annabelle Gurwitch (31:10):

To

Lysa Buonanno (31:10):

Do something. So I volunteered a lot. I've always volunteered with the homeless population. I volunteered with our animal shelter for a lot of years. I got a part-time job at the animal shelter eventually. Something very minimal, but I like to be able to ... I feel like you need something to still feel useful. Sometimes I feel like when you don't have your professional position, the way you interact with people, the way I support my community, I can no longer do that. So how do I fulfill that? A lot of that was volunteering for me, which was great. Also, I've worked two jobs a lot of times

Annabelle Gurwitch (31:50):

And

Lysa Buonanno (31:51):

I enjoy working. I don't know. I like being busy, I guess, let's say

Annabelle Gurwitch (31:54):

That. And useful to other people. I mean, in your job at the hospital, you were useful to other people and this is another way of doing that.

Lysa Buonanno (32:02):

I love being able to help the community and help people and of course love animals. So that was a great transition. But it's a good way to fill my time to feel like I'm making a difference in helping somebody. And I think that's also why I ... First of all, I was pissed off about the funding issue or lack of funding I should say within lung cancer. That was one of the reasons I wanted to get involved, but then stayed in advocacy and tried so many different aspects of it because that was just another way for me to participate in my community and to give back to other people.

Annabelle Gurwitch (32:40):

I want to talk about second opinions for a minute. One of the amazing oncologists at Memphis Baptist who we've both interacted with many times is Dr. Ray Osara Gilban and I love what he says about second opinions. He says, "If your doctor doesn't support getting a second opinion, you're not with the right doctor." And I also love what he says about what a second opinion can do. As a physician, he says when a patient gets a second opinion, either for all of us, it will confirm and give us the sort of extra energy and boost towards the line of treatment we're following. If it doesn't, then we all learn something.

(33:29):

Me as a profoundly wise man who I have taken his advice personally and I encourage mentees that I work with to do this because I think and for myself, I know I can feel like I'm failing the treatment, I'm failing this doctor and one of the things, one of the leaders in advocacy, Jill Feldman, has helped do a founder of EGFR resistors do is help change the lexicon used in the International Association for the Study of Lung Cancer, IASLC to say, "We must remember we now say we don't say a trial or a drug, you've failed, a patient has failed that trial or drug, the drug or trial has failed the patient." The drug has

Lysa Buonanno (34:25):

Failed the patient. And I think you're right. A lot of people feel that way like, "Oh my gosh, this isn't working for me. " And they feel some sort of like they had a choice in it, like they feel some sort of guilt or overwhelmed by the situation. But I think that's awesome that Dr. O, we say that in our community a lot, right? Yes. If your doctor doesn't want you to get a second opinion, you need a new doctor, but to hear a physician in that space also encourages it. It's really great to hear. And I also tell almost every new patient I speak to, "Have you reached out for a second opinion or where are you located?" I can maybe even help direct you to a facility or a doctor near you.

Annabelle Gurwitch (35:17):

One of my mentees was a candidate for surgery, a 3B diagnosis and the initial place he was at a fantastic cancer center doing what they felt was right. The initial plan was to immediately have surgery. I said, "Have you reached out for a second opinion?" Through the second opinion he was able to get on, he is an EGFR mutated oncogene driven cancer. He was able to get on Tagrisso, also do a round of chemo, shrink the tumors. So this meant right before the surgery, he lost a lot less lung and we want to lose as little lung tissue as possible. So just from institution to institution, different opinions and one of the things I do mention to my mentees is I give them a little language as a prompt to say, when you go to get the second opinion or even as you're working with your oncologist, it's important to know that since we have so many choices now, this is where shared decision making comes in, I try to say, "Here's some language you might want to think about and then address with your doctor.

(36:39):

This is my goal. How close can you get me to achieving this? " So what does that do for us? That means we have to actually say, because quality of life is a goal. What's important to me? And we know- That looks

Lysa Buonanno (36:53):

Different for everybody.

Annabelle Gurwitch (36:54):

It does. And the permission to have that discussion is something all patients deserve and sometimes requires a second opinion. So back to your story though, Lisa, you went to, well, how many lines is it now?

Lysa Buonanno (37:13):

I think it's five.

Annabelle Gurwitch (37:14):

Wow.

Lysa Buonanno (37:16):

Once I had progression, we did do a new biopsy, which is very important

Annabelle Gurwitch (37:20):

For people to have

Lysa Buonanno (37:21):

A new biopsy because you want to know why that drug is no longer working

Annabelle Gurwitch (37:25):

For you. Sometimes lung cancer can change. Lung cancer is just like a toddler sneaky. It's sneaky. You know when your kids are two years old, it's like danger Will Robinson, they go everywhere. You try to contain it, you can't contain it, then there's trouble. It

Lysa Buonanno (37:43):

Just wants to survive, right? It

Annabelle Gurwitch (37:44):

Wants to survive and it can change mutations.

Lysa Buonanno (37:47):

It can change mutations. You definitely need to know why because we are thankfully science has evolved so much that when I was diagnosed, there was one targeted therapy for ROS1. We are a pretty small population of lung cancer. It's only one to 2%. That's why you're the

Annabelle Gurwitch (38:04):

Wonders.

Lysa Buonanno (38:05):

So we are. That's why we do have less treatment options than some of the other biomarkers.

Annabelle Gurwitch (38:14):

Today, but hopefully soon.

Lysa Buonanno (38:18):

I mean, that's what I was going to say. It's amazing how fast really that it's

Annabelle Gurwitch (38:21):

Changing

Lysa Buonanno (38:21):

Right now and the momentum of now that they've ... The more they learn, I feel like it just opens so many more doors. So obviously continuing to fund research and investing in these newer treatments. But when I had progression, there were two new drugs available actually both in clinical trials but about to be approved within the same year, but it was going to require me to travel for both of them.

Annabelle Gurwitch (38:51):

Okay. This is a really big topic and it's so important because clinical trials are often the way to get into the most exciting, newest treatment. The most advanced

Lysa Buonanno (39:07):

Treatment

Annabelle Gurwitch (39:07):

At the moment. And patients worry about are they going to get a placebo?

Lysa Buonanno (39:14):

Yes.

Annabelle Gurwitch (39:14):

We also worry about the cost, the travel, and how to get there. Lysa B, tell us your knowledge.

Lysa Buonanno (39:24):

There's a lot to navigate and if you have an amazing doctor that's willing to do a lot of that leg work for you, so helpful. I did not at the time. I self-enrolled in the clinical trial, which was even challenging for me. I feel like I have as much knowledge as I do have about how the system works. And you

Annabelle Gurwitch (39:46):

Heard about the trial from where?

Lysa Buonanno (39:48):

From the other Ross Wonders. That's a great thing about these biomarker groups. So there's about a dozen, almost every biomarker has a patient group.

Annabelle Gurwitch (39:58):

And there are groups for people who do not test positive for biomarkers as well.

Lysa Buonanno (40:02):

People that are in immunotherapy, people that are in small cell or squamous cell carcinoma. There are groups and the amazing thing to me isn't even just the support that you're getting. It's the knowledge within those groups. I lived in Las Vegas where we did not have specialty oncologists. They were all community oncologists, but I had contact to the ROS1 experts or the EGFR experts. Because people within our group saw those doctors. Amazing. They shared that information with the rest of the population. So

Annabelle Gurwitch (40:37):

This is how you found out about the clinical trial you self-enroll, which can be done when you find out. You just contact the

Lysa Buonanno (40:44):

Sponsor and

Annabelle Gurwitch (40:45):

They

Lysa Buonanno (40:45):

Tell you what to do.

Annabelle Gurwitch (40:46):

So how did that work for you financially?

Lysa Buonanno (40:54):

Clinical trials are, especially mine, phase one, which means it's the first time in humans. Obviously they want to test safety so a very small number of people are enrolled initially. So it's usually in very few locations across the US two or three, eventually it'll expand to five or six. So that means most people are required to travel. If you could drive, I need to fly.

Annabelle Gurwitch (41:25):

There's

Lysa Buonanno (41:25):

A lot involved

Annabelle Gurwitch (41:26):

Logistics. And in the clinical trials, and you've been in several of them now, has your travel been covered?

Lysa Buonanno (41:34):

They didn't used to be. They did not used to be.

Annabelle Gurwitch (41:40):

One of the reasons why we think- We know that some populations are underrepresented in trials because they used to do that. I know many institutions are trying to address that.

Lysa Buonanno (41:54):

I want to say I feel like most of them probably do now. I can't say 100%. Yes. That was a huge thing that was advocated for over the years. Yes. Pharma, obviously they spend big money to develop these drugs, but they also make big money. And if they want to develop these drugs, they have to have patients in their trials. That's the way every single drug is passed through the FDA including Tylenol at one point. I'm

Annabelle Gurwitch (42:19):

Going to just mention in my book, The End of My Life is Killing Me, I write about you.

Lysa Buonanno (42:25):

You do.

Annabelle Gurwitch (42:25):

And things I've learned from you. And one of the things I write about is that you told me that in one of the trials you participated in, if it's okay for me to share this and you can say, "If it's not, we won't use this. " You told me, Lisa, and you gave me permission to write about this, which I thought was so generous of you that at one point as fantastic as it is that the clinical trial was reimbursing you for travel, it took months to get reimbursement.

Lysa Buonanno (42:58):

Yes.

Annabelle Gurwitch (43:01):

And that just broke my heart because I think about how we're already dealing with cancer. We need to make it easier for patients to participate.

Lysa Buonanno (43:13):

Absolutely. I mean, not many, first of all, like you said, taking time off work, rearranging daycare, whatever it is you need to do to get to your appointment. My mom used to go with me. We would go the night before, stay in a hotel because my appointments were very early in the beginning tons of extra blood work and exams and so my appointments used to be longer.

Annabelle Gurwitch (43:39):

Oh, and so yeah, let's talk about that process a little bit. When you're starting enrolling in a clinic, in a clinical trial, very often or at least in your experience, you have to go more frequently to the location and the reason why we think about that. Well, why do you have to go to the location? They want to make sure the testing is done in the same place to standardize and give the best results possible without risking having a variety of testing done. There are patients

Lysa Buonanno (44:09):

Involved. Yeah. So all the lab work, EKGs in the beginning, I've been did a vision test. I have to say for those that are afraid of or are apprehensive about joining a clinical trial, people throw the word, "I don't want to be a guinea pig." They throw that around a lot. And I think what we think of a typical clinical trial is there is a placebo that you get a sugar pill or I don't know what I'm getting. That's not the way they work in lung cancer

Annabelle Gurwitch (44:44):

Trials. Because it's so deadly, it's really important to mention that in lung cancer trials placebos are not given because that would not be ethical knowing the effect you would have. They

Lysa Buonanno (44:56):

Can't essentially just

Annabelle Gurwitch (44:57):

Say,

Lysa Buonanno (44:58):

"You're going to enroll in this trial, hope you get the drug."

Annabelle Gurwitch (45:00):

Yes. But

Lysa Buonanno (45:00):

If you don't, you're essentially on no treatment. Yes. So most of these trials and they're not even ahead to head, so that means they're not comparing the new drug to the other drug. There are trials like that, but most of the ones that our listeners would probably enroll in, you are testing the brand new drug. So like I said, in the beginning, phase one, there's only about 30 people. They want to develop, first of all, they want to know that it's safe, this isn't going to kill people and they want to test the toxicity levels along with dosage. So they start people on varying dosages, the lower dosages gradually get up to what they think their dosage will probably end up being, in my case, 100 milligrams. So there are people that started on 25, 50, 75.

Annabelle Gurwitch (45:56):

We should also mention that in most cases, as my understanding is, one of the fears is that people won't be able to continue the care at the institution they're at. That's not the case.

Lysa Buonanno (46:09):

Yeah. I still see my local oncologist

Annabelle Gurwitch (46:12):

At home. So in a way, you're getting two teams now. So it's not like you're giving that up and that's an important fear we need to address.

Lysa Buonanno (46:21):

Yeah. And a lot of them also allow you to do scans at home, which I do, thankfully, so I don't have to travel for that. I have my scan at home a few days before I fly out for my appointment, but with all of that and all of the ... And some people just don't like to travel. Like, what if you don't like to get on a plane? That's your only option.

Annabelle Gurwitch (46:43):

Yeah.

Lysa Buonanno (46:43):

So there's a lot involved. Many of them do give you a debit card or a credit card type to make your hotel and your flight purchases. I think that is the way to go. I don't know why they don't all do that, but there are still currently some that just do a reimbursement. I submit my receipts after my appointment. Like you said in the beginning, five months and I was flying there once a week in the beginning.

Annabelle Gurwitch (47:10):

You do the math people.

Lysa Buonanno (47:12):

I was $4,000 in before I got my first check and then it wasn't even accurate. So it was very frustrating to say the least. Patients should not be put under that

Annabelle Gurwitch (47:22):

Additional

Lysa Buonanno (47:22):

Burden.

Annabelle Gurwitch (47:23):

You know, one thing you also shared that I share in my book is that the way that it was structured for your meal allowances per day when you traveled meant that there were allowances for a certain amount per meal, but you couldn't use the breakfast allowance because you couldn't eat before the testing. So then there's this lunch allowance and you try getting healthy food at an airport- In an airport

Lysa Buonanno (47:56):

For 20 bucks.

Annabelle Gurwitch (47:57):

For 20 bucks. And that just broke my heart. And what I think about in terms of that is I think we still have more education to do in terms of doctors and medical professionals who are earning a living that they're not freelancers and they're people who haven't taken this hit to their identity where their finances have been impacted. They may not be thinking about exactly what it costs to have lunch and that this might be a factor. A simple adjustment in saying, "Here's a daily allowance for food that's not broken down by meal could solve that. "

Lysa Buonanno (48:55):

It's like $75 a day, but I couldn't spend $21 for lunch. I only got reimbursed for 20.

Annabelle Gurwitch (49:01):

Okay.

Lysa Buonanno (49:02):

I did get that change to be fair. I did have to- Well, fantastic. Can you move this to $30? This is silly. I only eat one meal. I'm gone for 14 hours from my home.

Annabelle Gurwitch (49:13):

So when I think about you and I think about you're doing these clinical trials and I think, okay, first of all, I'm going to cry for a second. You recently became a grandmother. This is something you've told me you didn't know if you'd lived to see, and I certainly can feel that way. I think my friend Lisa is a grandma and you're not going to give grandma. Who doesn't want their grandma to have a really good lunch? All you have to do is take the $75 and say- Make me

Lysa Buonanno (49:50):

I feel old now.

Annabelle Gurwitch (49:52):

Well, I'm older than you though.

Lysa Buonanno (49:55):

I'm happy to get older now. I have to say I'll be 55 next month. Being diagnosed at 40 years old, I didn't think I would be here. There's still some work to do for sure. There's just some work to do because I want you to have a great lunch. It's changed a lot already. And I really think that is just from patients speaking up. It's okay to tell them, tell your doctor. Doctors like to advocate for us as well. Yes. Tell your doctor like, "Man, did you even know? " Because they don't know they have enough other things to do, right?

Annabelle Gurwitch (50:24):

Yes.

Lysa Buonanno (50:25):

That's not their end of it.

Annabelle Gurwitch (50:27):

Well, one of the things we know is that it's because of conversation with our doctors that we are getting better care. Dr. Brendan Stiles at Montefiore Einstein, amazing thoracic surgeon said to me, "We wrote a conference, there's a plenary with Dr. Nargis Flores. I think you're going to be interested in what she's doing." I couldn't believe it. I was weeping and I stood up and announced in front of everyone gathered online and said, "I have a dry vagina for my drug." And I gave her a standing ovation. I was crying. It was kind of like, we were like, "Oh my God, okay. She's like- She sees me.

Lysa Buonanno (51:16):

Yeah. It

Annabelle Gurwitch (51:16):

It was like, you see me. " But this has changed the landscape for so many of us. It was a question that hadn't been asked. And so how do we make change? First of all, we invest in science,

(51:36):

Elect our elected officials in our government to fund- Support the contained science. And who support vetted scientific methods and we as patients can, I was going to say empowered, participate and advocate for ourselves. I think we're going to close out this episode, Lisa, but you've been a leader in our community for 14 years now. I wouldn't be having the quality of life that I'm having without you on the macro level, the little work that you do, but I also text you and call you on scandals sometimes. And I can't even tell you how much that means to me, but I think you know. And I wish for everyone listening to find the connections that we know are keeping us so resilient and also knowledgeable and make this survivable together. I think

Lysa Buonanno (52:52):

This can be a very scary diagnosis and people can feel very alone,

Annabelle Gurwitch (52:57):

But

Lysa Buonanno (52:57):

I also have found so many silver linings through this disease in this community.

Annabelle Gurwitch (53:03):

Many silver linings. It's true. Thanks for listening. Thanks for being with us, Lysa B.

Lysa Buonanno (53:10):

Thank you.