Lung Cancer Foundation of America

Hope With Answers: Living With Lung Cancer

Transcript for
The Hidden Battle: Lung Cancer Stigma and the Power of Speaking Up

Ava (00:00):

Welcome to a special re-release of The Hope With Answers podcast originally released in January, 2020. This episode tackles a unique and damaging burden lung cancer. Patients often carry stigma from unsolicited comments to assumptions about smoking. Patients like Jill Feldman have heard it all In this powerful episode, Jill is joined by journalist Steven Petro to explore how to respond to the things people say. Plus, lung cancer researcher Dr. Alice Berger shares important insights into why young, non-smoking women are being diagnosed with lung cancer, helping to shift the narrative and drive progress.

Diane Mulligan (00:42):

Welcome to The Hope With Answers Living with Lung Cancer Podcast. We are so glad you've joined us today, and I am

Sarah Beatty (00:49):

So excited for this episode. We are going to hear from LCFA advocate, Jill Feldman, who has a

Diane Mulligan (00:57):

Lot to say she does, and she's amazing. She was recently featured on The Today Show. She's just a tireless advocate who helps people understand the importance of biomarker testing through her work in the EGFR lung cancer community. That's EGFR. It's a tumor marker. And, and she's a fearless warrior against what we call the stigma. Stigma. Anyone in the lung cancer community can tell you about the devastating stigma of having this disease. It's, it's almost as if lung cancer patients are blamed. Imagine this blamed for their own cancer, because they're automatically asked, did you smoke? Did you smoke?

Sarah Beatty (01:35):

That's the very first question, and that's a devastating and very often inaccurate stigma that Jill tackles head on with civility and manners expert and healthcare and science writers Steven Petro. So let's just start at the beginning with Jill's story. Jill Feldman, thank you for joining us this morning. I really appreciate it.

Jill Feldman (01:58):

Thank you for having me,

Sarah Beatty (02:00):

Jill. Unfortunately, you have, um, not just a personal history with lung cancer, but a family history with lung cancer.

Jill Feldman (02:07):

Yes, I do. I have been fighting lung cancer indirectly, indirectly for about 36 years. Uh, when I was 13, two of my grandparents died of lung cancer within weeks of each other. And then six months later, my dad was diagnosed with lung cancer, and he died three months later at the age of 41. And then in my twenties, both my mom and my aunt died of lung cancer. My mom died just six months after she was diagnosed at the age of 54, and my aunt died two years later at the age of 56. And my family felt helpless. My family felt hopeless, and it was just a horrible feeling, even though wasn't any research. I knew that our familial lung cancer wasn't just a coincidence. It was really a tough place to be in because I needed to find a way to redirect my anger and bitterness into, you know, some positive way.

(03:21):

And so I got involved in advocacy at that point. And one of the other things that was really important to me and really helped me is I found a community that understood and didn't judge. So with lung cancer, my dad dying three months after he diag he was diagnosed, my mom died six months after she was diagnosed. That was the norm. Patients didn't live very long. So I think that's part of the reason there weren't advocates. But the other part was the stigma. At anytime people, I would say that my mom, dad, and grandparents died of lung cancer. I would get that dreaded question of how long did they smoke? I didn't know they smoked. And it was horrible because you're, you are grieving. You just watched someone you love, suffer till their last breath, and now you are suffering. Yet you're made to feel as though you don't deserve any sympathy.

(04:28):

And whether they smoked or not, it doesn't matter. What matters is that somebody had gone through this horrible experience and it, what matters is that no one deserves to die of lung cancer. No one deserves to be diagnosed with lung cancer. So I was grateful to find this community that understood and didn't judge. The other control that I had was to be my own advocate. I did not want my kids to ever go through what I went through and lose a parent at a young age. So I had periodic scans, and when I was 39 years old, I was diagnosed with bone cancer. I had four small kids at the time, they were 6, 8, 10, and 12. And even though I had been involved with advocacy for eight to nine years, there still wasn't any convincing research that my path would be different than my family's.

(05:39):

There were some advances, but nothing that was really promising. And so the first, I would say eight years I was involved in advocacy, it, it really, research was moving very slowly. There wasn't funding to, to get researchers to even go into the field of lung cancer. So when these young scientists are coming outta school, it's not that they don't choose to go into lung cancer, it's that they have to make a living and they have families. So if the money's not there, they couldn't do it. And as time went on though, it really took off. I, I, I can't even explain. There aren't words to describe what it has been like to witness and celebrate the accomplishments, the creation of this incredible lung cancer community. And the research part of it, especially in the past five to seven years, there have been more advancements than in the four decades prior decades.

Sarah Beatty (06:54):

What is it like for you when you made that your goal when you were diagnosed? I don't want my children to lose a parent so young, um, knowing or being able to see, to witness that that might be the case, you know, that you, that you have, uh, access to, um, research and treatments that didn't exist when your folks were diagnosed and absolutely hadn't, weren't even a, a thought when your grandparents were diagnosed.

Jill Feldman (07:25):

It's interesting you asked that question because I didn't necessarily feel that way at first. When I was first diagnosed, I was filled with fear. And originally I actually, they thought I was stage one. So I thought I was diagnosed early. I could be the poster child of early detection, the story of hope that lung cancer patients and their families desperately needed. Uh, but soon after that, I realized that wasn't the case, and lung cancer was going to be a lifelong roller coaster ride for me. And so at the time there, they were just learning about oncogene driven cancers.

Sarah Beatty (08:10):

Sure. And so you wouldn't know about your grandparents or your folks even, but you, um, your lung cancer is a, a specific type, right?

Jill Feldman (08:21):

Yes. When I was diagnosed with lung cancer in 2009, they were just looking at the cancer when people were diagnosed to see if they had certain biomarkers. And the type of cancer that I have is EGFR positive lung cancer. It's epidermal growth factor receptor, and nobody needs to understand what that means. But it, except for the fact that that EGFR gene is what is driving the lung cancer in me.

Sarah Beatty (09:01):

And that makes you, um, and anybody else who has EGFR lung cancer eligible for what's called a targeted therapy, which is a drug that is made specifically for that type of cancer.

Jill Feldman (09:14):

Yes. And when I was first diagnosed, they were, they were just figuring out that there were these targeted therapies that could work specifically on that type of lung cancer, and they happen to be a oral pill that a patient could take every day. So it, and they were fundamentally different than the traditional therapies because they targeted that specific cell, that specific gene. Therefore, it almost, it spared other areas of your body.

Sarah Beatty (09:59):

So this is a total different thing than your grandparents and your folks had access to. They had chemo and radiation, and we all are fairly familiar with those side effects. Wonderful. As those treatments might be. You are talking now about a completely different kind of treatment called a targeted therapy.

Jill Feldman (10:18):

So when my grandparents, my mom, my dad and my aunt were diagnosed, there were three treatment options. Doctors had three treatment options to offer every single one of their patients. And as you said, it was chemotherapy, surgery, radiation, and many times the side effects of the treatment were worse than the disease itself with minimal benefit. So here we are now, research is just starting in about 2004 or oh five is when the discovery was really starting to take off. It took a while, but you know, they had to really look at these genes and figure out what the best treatment would be. Now with the discovery of different biomarkers, physicians and patients can make treatment choices that are more individualized, that will treat the type of cancer they have. And so that is where research has really taken off in lung cancer. And the advancements in treatments ha have allowed patients to live longer and better lives.

(11:43):

I don't think everybody understands how critical that is. And I know I didn't understand it when I first got involved in, I remember, you know, being angry and wondering, why doesn't lung cancer get the same amount of funding? It kills more people, and why aren't more scientists going into lung cancer? What is it not a glorified cancer like some of the other ones. And I remember vividly talking to a researcher at a local hospital here in Chicago, and he had started with four other young investigators, young scientists, and the four other ones were no longer there a couple of years later. And I remember saying, what is lung cancer not good enough for them? And he said, Jill, you are looking at this completely wrong. They chose to go into lung cancer, but there wasn't funding to keep them there. They have families they need, need to make a living as well.

(12:59):

So if they don't get funding for their research in lung cancer, they have to get funding in a different cancer. And it was the first time that I realized, oh my gosh, it's, it's, we really need to fund these young scientists and researchers, and they, they're the future of lung cancer. And the established scientists will even say that themselves. Yes, everybody wants to fund this. Uh, the work being done by these established, uh, scientists because of their track re record or because their name is well-known or the project they're doing is exciting. But it is critical to understand that the future of lung cancer depends on those young scientists, young investigators. So that work is very, very important.

Sarah Beatty (14:02):

I could, you just are so eloquent at explaining that. I'm so glad that you brought that up because that really kind of is the crux of, of what we're talking about here. Research is leading to incredible advancements. And these incredible advancements are making all the difference for you personally, um, from what you have seen your, your parents and your grandparents go through. Unfortunately,

Jill Feldman (14:31):

Yes. And when I personally, I, it's, I was diagnosed almost 11 years ago in January, and when I had progression last year, I, I was not happy. I was upset, of course. Um, but it was the first time that I had to make a treatment decision where I was not overcome with fear. And that is huge. I was surprised that I was not overcome with fear. The reason I wasn't though is because I had a very durable option and I had something that I could go on that, that really worked. And there was research that proved it worked. And I know that there's other stuff in the pipeline, so it's not like before where I'm like, oh my gosh, what am I gonna do next? And that is how I felt before those feelings is what really told me how far we have come. And so one of the other things that I learned throughout the journey also was that there is hope in lung cancer finally. And I never used to use the word hope in the same sentence with lung cancer, because in my experience, there wasn't any. And about five years ago, I started using the word, and I actually have used it more as time has gone on. And again, that surprised me that I was actually using that word. So I had to really think about why am I using this word now? And the truth is because research is hope. That is what gives patients hope. That is what allows us to live longer and better lives. And advocate,

Sarah Beatty (16:37):

Jill explains the connection between lung cancer research and hope so incredibly well, she really does. Research is the path to a hopeful outlook for someone with lung cancer

Diane Mulligan (16:50):

Research equals hope. Absolutely. She encapsulates the connection so well, and you heard her mention her advocacy work and that smoking stigma that she battled in her own diagnosis. I think it was even more frustrating for her because if you can imagine this, her parents, aunt and grandparents mm-hmm <affirmative>. Were also all diagnosed with lung cancer.

Sarah Beatty (17:17):

Unbelievable. She's been working on this stigma for years, and that's a big part of her work as an advocate now. And up next, I am so excited to have you here, this conversation. Jill and I talk to an expert in manners and civility so that friends, family, coworkers, anyone whose life is touched by someone living with lung cancer, really any cancer Yeah. Has some help in handling some

Diane Mulligan (17:45):

Of these situations. Wouldn't that be helpful? Well, and you need that help. Mm-hmm <affirmative>. Because when somebody, especially when they first tell you that they've been diagnosed, you don't know what to say and you don't wanna say the wrong thing. So sometimes you don't even say anything at all. So this is going to be,

Sarah Beatty (17:57):

We go through it.

Diane Mulligan (17:58):

Yes. This is gonna be great.

Sarah Beatty (17:59):

That's up next.

Diane Mulligan (18:02):

We hope you're enjoying the LCFA Hope with Answers Living with Lung Cancer 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 increase the public's awareness of lung cancer status as the leading cause of cancer death, inform and educate lung cancer patients in their lung cancer journey and fund innovative lung cancer research. Many of us have been there, someone you care about can remember several friends of mine telling me for the first time that they had cancer. Mm-hmm. Maybe a family member, maybe a colleague or a friend, tells you they're facing that scary diagnosis right now. Quick, what are you gonna say? Mm-hmm <affirmative>. You better say the right thing. But what if you wanna know more? You don't even know if you should ask. Mm-hmm <affirmative>. Maybe you're too stunned to say anything. Maybe you blurred out the first thing on your mind. That's what I do. Oh, maybe that wasn't the right thing to do. <laugh>. <laugh>. Yeah.

Sarah Beatty (19:09):

Yikes. I have been in so many of those situations and have felt so unprepared.

Diane Mulligan (19:17):

Yep.

Sarah Beatty (19:17):

For what to say next. And I've said things that later I look back and think, oh,

Diane Mulligan (19:23):

Or I've read the people's reactions to the things that I've said and thought, oh my God, I said that. I said that.

Sarah Beatty (19:29):

I didn't mean to say that. You mean? Yeah. So we've all been there. And it could be lung cancer, it could be cancer, it could be any kind of illness. Many kinds of challenges. Don't you wish you had some

Diane Mulligan (19:41):

Help? That's right. Right. Gimme the words to say,

Sarah Beatty (19:43):

Give them to me. So that's the heart of our next conversation that I had with Jill Feldman and Steven Petro manners and civility expert, and also a cancer survivor, and a, a health and science writer. So I can't wait for you to hear this conversation. Take a listen. Thanks for joining us. Steven Petro, you're a manners and civility expert and a health and science writer. Thank you so much.

Steven Petrow (20:10):

Glad to be with you both today.

Sarah Beatty (20:11):

Thank you. And Jill Feldman, you and I had such a great conversation, um, the other day for, for this podcast. And you're a patient advocate with the Lung Cancer Foundation of America. I think I'm so excited for this conversation. Thank you both for joining us.

Jill Feldman (20:27):

Yes, thank you, Sarah.

Sarah Beatty (20:29):

Super. Well, we have talked, um, we sort of go round and round with some of these things, and I put out a call to members of the speakers bureau and said, what are some of the, the things that people have said to you? And my goodness, the emails that came back, you cannot believe. And so I'm so excited to have you, um, weigh in on some of these. You're a cancer survivor yourself. And so unfortunately you've got some experience with some of these things that people say

Steven Petrow (20:57):

That is true. I'm a long-term cancer survivor. I had testicular cancer when I was in my twenties. And I, you're, you're leading me to remember all of the questions I got about my testicles, they suddenly became like public property <laugh>. Um, and, uh, friends of mine who subsequently had breast cancer said, you know, after they had, um, their treatment, their breast became like part of this, um, large conversation. And it's, it's a little bit, um, um, unnerving. Uh, I have found over the years that people, they don't mean to do anything, um, un tour, but they, they get nervous. Uh, they don't know what to say. And so something pops into their mind and they, and, and they say it. And I think that's probably why we're having this conversation today to give people, um, a plan B and a plan C.

Sarah Beatty (21:46):

I love it. And I'm sorry that happened to you, but I know exactly what you mean. <laugh>, <laugh>, I can't tell you the number of times I've stuck my foot in my own mouth.

Steven Petrow (21:56):

And likewise, I try to practice what I preach, but I'm, I'm a human being too. And emotions and other things, you know, get caught in a situation and, you know, it can be hard.

Sarah Beatty (22:06):

Yeah, I think that's a great point. Well, here are some of the things, and I'm just gonna rattle off a couple of them and we, we can talk about them. Um, so these are some of the responses that people, members of the Speakers Bureau have gotten before. Um, there's a lot of questions about prognosis. Um, you know, what's your prognosis? And I think that, you know, comes from a place of, of trying to show empathy, trying to show that you're engaged and interested. Somebody was asked, does this mean you're going to die? Some people who have, um, no evidences of disease is what it's called in, in lung cancer, are asked, oh, you're in remission. Isn't that great? Now you don't have to worry about it. Some people have been asked, oh, it's, it's like a chest cold. Didn't you catch this sooner? You know, all sorts of, um, I don't know, like treatment questions and, and, and statements. And maybe Jill, you can talk about can, how those statements sound to someone living with lung cancer.

Jill Feldman (23:02):

Yes. Uh, I, I actually get those statements a lot as well. And it's really, it's really upsetting because it makes you feel almost worse when you know that your, the cancer you have cannot be cured. And that is the reality of lung cancer. There's probably 15% that have the, the cancer caught early, and they can have surgery and be cured of that cancer. Uh, truthfully, about 50% do have recurrence of that cancer or another primary lung cancer at some point. But the other 85% of us diagnosed in advanced stage cancer, there is no cure. And there are these new therapies out there, these targeted therapies especially, that allow patients to live longer and better lives. And they don't have the traditional side effects that the chemotherapies had, but they don't come without cost. They still have side, side effects that affect quality of life in everyday life. And one of the things, and I don't know, Steven, you probably agree or have experienced this as well. I think one of the thing, one of the reasons that people say some of those things to you is because it makes them feel better. It makes them feel as though they wanna think you are going to be okay. And it's really hard as a patient really hard.

Steven Petrow (24:54):

I think that is, you know, definitely part of it. And that's, that's not a bad thing. You know, we, we all want everyone to <inaudible> forever, but, um, as, as, as we know, that's not the case. In fact, everyone dies at some at some point. So, you know, again, I think it comes from, from a good place, it goes awry. And I also think that when we're having this question, talking about this question, there are different levels. So, um, or I'm thinking about different, um, types of family members or colleagues. So a question, you know, if your child is asking questions about, you know, how are you really doing? You know, if it's a teenager, what is your prognosis? I think, you know, you're gonna want to speak differently and probably either more directly or in concert with a therapist about, you know, what's age appropriate and how can they handle that? That is information that, uh, a child probably needs to process really different than a colleague who does not need that information to, um, continue. And, um, so I think we sort of keep to sort of break down the groups that we're talking about too, in terms of what's, what's okay to ask and, and, and what's not. But I think a general rule, and I I I would think you would agree is follow the lead of the person who has cancer. They will open certain doors and they will not open certain doors.

Jill Feldman (26:10):

Absolutely. I think you're absolutely right on that. There are people who don't necessarily wanna talk about it. And I am definitely a person that I wanna get that elephant in the room out <laugh> mm-hmm <affirmative>. And so I want to be honest without being a downer. And I think everybody handles it differently. And I think truly that when somebody looks healthy and they feel okay, we can't necessarily expect them to understand the reality of what we are going through.

Steven Petrow (26:49):

You know, a lot of times when people ask, you know, how are you in any situation, it's really a formality. They don't actually wanna know the answer. And some of our answers are actually, you know, complicated and nuanced.

Jill Feldman (27:00):

Yeah, right. I, I a few times said, do you want the truth or do you just want me to say, okay, <laugh>?

Steven Petrow (27:07):

Yeah. And sometimes we have to figure out which is the, which is the direction we wanna go.

Jill Feldman (27:12):

Exactly.

Sarah Beatty (27:13):

I think that's a wonderful point of view. What do you think about a situation, you know, where you're in a social situation and you know, someone says, oh gosh, I heard you were sick, or This is one we hear a lot. Um, you look great. I can't believe, I mean, they're basically saying, I can't believe you have cancer because you look so good. And I, again, I think that people are trying to connect, they're trying to be positive, they're trying to be, um, supportive, but those are sort of prickly situations.

Steven Petrow (27:43):

You wanna take that one first, Jill, because you look terrific.

Jill Feldman (27:45):

I <laugh>. Thank you. Yes. You know, it, it is something that people say again, I think what, when you're talking to a lung cancer patient who is fortunate to be, um, one of the newer therapies, whether it's a targeted therapy or an immunotherapy, the side effects are not the traditional chemotherapy side effects where you lose your hair. And I do think that that image, it correlates with more of a cancer patient. But I, you know, I am a patient that had ser had severe side effects from the targeted therapy at a lower my dose, and I still have them. And so I think one of the things that I've answered before when I've been, you know, when somebody has said that and I know I don't look great or I just don't really feel great, I will say, I wish I felt as good as you think I look and, you know, kind of giggle. Because again, that person, unless you really do look horrible, that person doesn't know what else to say and they are surprised and they do think you look great. So that's something that I'll say. And then sometimes I take that opportunity to educate people about the side effects and how they differ from person to person. And my scan doesn't always validate the physical appearance <laugh>. So it is an educational moment as well.

Steven Petrow (29:27):

And I'm gonna, we'd obviously just met, um, but I'm gonna guess that, um, you like me feel that in some way you're an AM ambassador for your type of cancer. Yeah. And um, you know, and this has been many years for me, it's one of the reasons that I, that I still write about it, and I wrote about my, my mother's disease, my mother's journey with lung cancer was, was to educate and also to show that there are many different faces of this disease

Jill Feldman (29:55):

Mm-hmm

Steven Petrow (29:55):

<affirmative>. And, you know, we sort of associate someone who's lost their hair and has lost a lot of weight and it's, it's on the outward physical detriments. That's the judgment we come with. And so I

think part of this conversation is there are many different levels to that, and there are times when we can do that education.

Sarah Beatty (30:11):

Right. Well, I think that's such a wonderful point. And, and that's the reason that we've brought both of you together today is sort of to, to look for the opportunities that we can take to educate. And I think that's a great segue into maybe the most difficult thing we have to talk about today, which is wrestling with this smoking stigma. So after someone says, oh my gosh, you know, I didn't know. And you know, the first part of the conversation, usually, Jill, what's the second question?

Jill Feldman (30:39):

Did you smoke? How long did you smoke any other cancer? Someone says, I am so sorry, what can I do to help? But with lung cancer, that's not it. It, it goes directly to this stigma.

Sarah Beatty (30:55):

You and I've talked about this, but how does that feel?

Jill Feldman (30:57):

It puts you immediately on the defense whether you've had a smoking history or not. It doesn't matter. No one deserves lung cancer and no one deserves to die of lung cancer. But when you, what you're going through emotionally when you're initially diagnosed, and that's the question thrown at you, or if it's a love to one of yours that has lung cancer, they will still ask you the same question. And so even as a loved one, it it, it really puts you on the defense and makes you feel as though they aren't sympathetic at all. And so it's something hard that we really, that I've, I struggle with a lot because I think it's divisive within our lung cancer community because anyone with a smoking history at all then feels as though they are to blame. And why are these other people who don't smoke not getting lung cancer when the reality is there are other risk factors to lung cancer and all you need are lungs to get lung cancer.

Sarah Beatty (32:15):

Yeah. That's, that's the phrase that we come back to is all you need are lungs. Steven, from an etiquette point of view, and from looking at this as an opportunity to educate, where do you go from there? Where do you go from that question?

Steven Petrow (32:30):

I'm gonna take a step back before that question. For people who, you know, who will find themselves being told by a loved one, by a colleague that, that they have lung cancer, don't ask that question about smoking. Just don't. Normally what we would do is express some form of, um, compassion or empathy, which may take the form of words or a hug if that's the kind of person you both are. And, and, and hugs can be very convenient because when someone tells you news like that, they actually may have become a little bit, um, well versed if you're, um, you know, seventh on the list. But for you it's a shock and you know, and you're trying to hear this and process this. And that is why people will say things that they wish they hadn't said. But, uh, I believe in sort of taking a pause, collecting yourself and, um, expressing empathy when you can and, and or a hug. And now I forgot the question you actually asked me. <laugh> <laugh>.

Sarah Beatty (33:26):

Well, um, that's a wonderful answer. Thank you. Um, I mean, how do you use this as an opportunity if you think it can be used as an opportunity to educate?

Steven Petrow (33:37):

You know, in my, in my experience and, and being around, you know, family members who've had cancer in the, in the telling of a diagnosis, most of us are not, you know, really up to speed on our education platforms. You know, it's new to us. We may not actually know as much as we will come to know later or not. So, um, I, I don't like that to be a burden on the person who is ill because that's, that's another burden. And I don't want to do that to people. You know, if someone is comfortable with that, sure. You know, use it as an opportunity. But this is a highly charged moment. And, um, and I don't think it's best, um, you know, for doing education 'cause people will also have trouble hearing it when they're also learning for the first time that you have cancer. Jill, what do you, what do you think?

Jill Feldman (34:25):

You know, I, I, I'll tell you that I, a lot of times I think now when patients are diagnosed, they really, they, you know, they're, they're angry and that's really offensive to them. And instead of ha being in a place to educate, 'cause like you say, if it happens, you know, when they're newly diagnosed, they're not in that place always to educate. So it's more of an answer that comes right from, you know, the anger inside of you. And of course you're scared. I, I remember before I was educated, I got that question about both my mom and dad did they smoke, and I was bitter and angry. And, and, and I remember my, a lot of times my reply would be, does it matter, you know, kind of in a, a negative way? And so as the years went on, what I learned to do was, I didn't like to make people feel uncomfortable.

(35:32):

I know people's intentions are most of the time to see whether they're safe or not. I feel like, um, you know, wanting to know if there's this behavior, you know, relation, but I know their intentions aren't bad. And it really, they've done such a great job with smoking cessation and prevention, that that's how the stigma developed. Not any other way, unless it was perpetuated through family or school. So they can't help it. And I think that it might take a while to get there, but once you realize that there, there's not bad intentions, you don't wanna make them feel horrible or put them on the spot. So I do often now what I'll do is I'll say, uh, you know, kind of in lighthearted way, I'll say, I wanna ask you a question first. I'll, I'll tell you Yeah. Whether you know, I smoked or not, but I wanna ask you a question first.

(36:35):

Why are you asking? I'm just curious. Why are you asking? Because if I was diagnosed with a different cancer, you wouldn't ask me whether or not I, you know, partake in, you know, in this behavior. So I'm just curious. And a lot of times people will stop and say, oh, I don't, I, I don't know. And so that's exactly proves the point that they don't know what else to say. And I don't think that when somebody is really newly diagnosed or right, that they are in a place where they can be calm about it and ask it that way.

Steven Petrow (37:19):

I'm also a big fan of sites like CaringBridge, where you have the ability to form a community of people you choose and you choose to allow it. And that's a great communication platform where you can say what you want to say and how you want to say it.

Jill Feldman (37:34):

Mm-hmm

Steven Petrow (37:34):

<affirmative>. And for some people who are better at expressing themselves, you know, while typing, um, you can respond that way too. And others will see that who are in your group. And so you're kind of getting a lot of bang out of your buck, so to speak. Not that it costs

Jill Feldman (37:49):

I see that too. You're right Steven. I see that a lot within the lung cancer community. Some people are much more comfortable with writing, and I think that that is a great way to express and then it's out there so nobody can misconstrue your words or misunderstand what you're trying to say. And that is really a great form of communication, I think, in these, you know, situations. And I wish, you know, I wish there was a way, I wish there was some way that everybody could answer that would not put the burden on the patient. And it just is a really hard situation. And I, I really do feel as though that has been divisive within our community a little bit. I feel like anybody who was an advocate before that had a smoking history, they are shaming and blaming themselves and they don't deserve lung cancer and they don't deserve to die of lung cancer. So, because I've been in this for so many years, that part makes me really sad. But on the flip side, when somebody's newly diagnosed, I totally understand their reaction.

Steven Petrow (39:09):

I mean, I'll just say this is a, as a personal story. So my mother had to been a lifelong smoker. And the advertisements and, and the addictive nature of, of cigarettes were part of that. And while we were growing up, my brother and sister and I, we wanted her to stop smoking. And we were loud about that from the day she was diagnosed, though that was over. It did not matter anymore, period. And, um, you know, I was really proud of my brother and sister. We didn't like have a conversation about that, but like, we're turning the page now and we're here with you, mom, whatever you need. And past was the past.

Jill Feldman (39:43):

So none of you said, I told you to quit smoking.

Steven Petrow (39:47):

Not to her. We said it behind her back to each other as s mouth, but not to her.

Jill Feldman (39:52):

Not to her. And that is amazing because I hear stories where people's children have said directly to them or their spouse, I told you, you should have stopped smoking. And that's, again, somebody's suffering and dying and they're feeling horrible that, you know, that like, it, like the disease was self

Steven Petrow (40:20):

Infl. That adds another layer of, of shame and it's unnecessary. It's cruel.

Jill Feldman (40:24):

Yeah, it really is. And I think the bottom line is we need to figure out a way to educate people about the realities of lung cancer. That's the only way the stigma is going to go away. If we start talking about lung cancer, let's, you know, change the conversation, stop talking about smoking, start talking about lung cancer. And when we talk about risk factors of lung cancer, then of course that's where you can talk about smoking. But the diseases really needs the awareness, and that's what we need to educate the greater public about is lung cancer.

Sarah Beatty (41:11):

So putting it in the right context Yeah. In context of risk

Jill Feldman (41:15):

Factors and that, because it is true and nobody's denying that, but you will find lung cancer patients don't wanna, you know, don't even wanna hear about that risk factor because it's so, it's so in our face. And it's interesting, you know, I, I wrote a blog about it one time. Um, let's kill the stigma and Save lives. I've written a couple about it, but I had to really, really think about the stigma. And that was when I was thinking about how it was divisive within the community. But one thing that came to mind is it's going to be really hard to completely get rid of a stigma that we are characterized by. We're either a non-smoker, a never smoker, a former smoker, or a current smoker in our, um, doctors, you know, when in our healthcare, and they have to know, they have to know. That's something important that doctors need to know.

Steven Petrow (42:19):

Sometimes the way they ask, were you a smoker? Are you a smoker? The tone, the facial expressions also convey shame rather than simply trying to, you know, solicit information. And so medical practitioners really, I think also need to pay attention to this question because they don't mean to be shaming, but, but they can be.

Jill Feldman (42:41):

Yes. And I have to tell you a real quick story. My husband and I were at the final for a couple of years ago, so we had these great seats. It was the championship game. And at halftime, I just started sweating, went to the bathroom, and I fainted. And so, you know, you have 60,000 people in at halftime in the Final Four, right? So my husband thankfully was right outside, uh, the ladies' room, but while they were waiting for EMS to get there, there was a really nice nurse and a really nice doctor who were sitting there with me and talking to me. And, you know, everyone asked if had underlying health problems, of course, I said, no, I don't know why. But when the EMS people got there and they said, are you diabetic? Could you, you know, asked all those questions, do you have any underlying health problems? And I said, my husband gave me the eye. And I said, well, yes, I have lung cancer. And the wonderful nice doctor that was helping me, she goes, are you still smoking? Jason is like, she is lucky that you were on the ground. And I, I did, I looked at her, I said, I don't smoke and I didn't wanna go off on her. But even in today's day and age, recent years, they still, doctors still assume,

Sarah Beatty (44:09):

Well, I mean, this is such a challenging topic and, and we talk about this a lot. Um, so I, I love the idea of helping to frame smoking as one of the risk factors because that puts it where it belongs. Mm-hmm <affirmative>. In the list of risk factors and not in, you know, frontline question or, or immediate response to somebody's diagnosis.

Jill Feldman (44:33):

And a lot of, you'll see a lot of advocates now, um, ones that I really have worked with a lot over the years, uh, they will say, instead of, I didn't even smoke, they will say, I did not have any known risk factors.

Diane Mulligan (44:52):

I love how Jill frames that response to the smoking stigma question. I didn't have any known risk factors because as we know, while smoking is a risk factor, it's not the only one. And all it takes to get lung cancer are lungs. Yeah. We say that

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Sarah Beatty (45:08):

All the time. That's right. What I love so much about the conversation with between Jill and Steven is that both of them bring their life experience and expertise to some really thorny interpersonal situations. Yep. And as a matter of fact, we covered so much ground that we had to break the interview into two parts because we just KI mean, unsurprisingly, we just kept talking and talking and I can't wait to bring you the second part of our conversation.

Diane Mulligan (45:35):

Wait, you kept talking and talking. I know.

Sarah Beatty (45:37):

Are you surprised? <laugh>? I'm not surprised. I might be a little chatty, but we had so much to cover. And so in the second part of our conversation in, in the next, uh, podcast we talk about, and I'm so guilty of this, attempts at humor gone terribly wrong. Ooh, <laugh>, it doesn't sound good. No. And some things that you can say or better yet do that will help someone facing a potentially life-threatening

Diane Mulligan (46:10):

Situation. These are such great tips and topics for conversation. I can't wait to hear them in the next Hope with Answers Living with Lung Cancer podcast. What more with hope, with answers, visit us online@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. So far in this podcast, we've heard from Jill Feldman, who we love and who is amazing Yeah. And has taught us so much about her work to combat the smoking stigma around lung cancer and how she's just the most wonderful advocate for lung cancer research.

Sarah Beatty (46:57):

We have had a rollicking conversation between Jill and Steven Petro about some ways to handle talking to someone about their lung cancer diagnosis. So now let's hear from, uh, an LCF, a young investigator about her work that focuses on non and never smokers. And we'll get into that difference. And particularly lung cancer in young women. And man, we know a lot

Diane Mulligan (47:26):

Of young women, unfortunately. Yeah. And they're healthy, healthy. I mean, if you took a look at them, you're like, this makes no sense

Sarah Beatty (47:32):

Whatsoever. Yep.

Diane Mulligan (47:33):

So, Dr. Alice Berger is a lung cancer researcher at the Fred Hutchinson Lung Cancer Research Center in Seattle, Washington. And she's using a treasure trove of data from the Women's Health Initiative. And that Women's Health Initiative has been so, it's provided data for so much research in our country. It's amazing. As part of her LCFA grant research,

Dr. Alice Berger (47:56):

I was inspired to be a lung cancer researcher after learning about the discovery of EGFR mutations and the recognition that only patients with tumors that have that type of mutation respond to EGFR targeted therapies. And that totally revolutionized the way that, um, cancer patients are treated with lung cancer. And then since that discovery, which was only 15 years ago, there have been dozens of other drugs, maybe even more, that have, um, been linked with different genetic alterations. And so now you see it, new drugs coming out all the time. And for patients that can mean one more option, you and I have worked on a Hope

Sarah Beatty (48:38):

With Answers video series where, uh, lung cancer patient activists get to talk to people like you. Um, investigators, they get to talk to top thoracic oncologists, um, surgeons, thoracic surgeons, and the patients get to ask the questions. What is it like being involved in that hope with Answers project? And what do you like about it? Why do you keep, why do you keep helping us do these, you know, crazy questions when we come to you and you so graciously say yes?

Dr. Alice Berger (49:09):

Well, it's been fantastic to meet these different patient advocates, get to know them, get to hear their, their story. And in so many ways, I relate to them. A lot of times we're the same age or we have have similar to families and things like that. And I'm just on the other side of the research and they're on the other side of the kind of clinic. And I learn so much from them about what they've been through and what kind of research is important to them, they wanna learn from us. And so it really keeps me focused on what my goal, my end goal is, is helping, um, more people have the good responses that some of these ladies are seeing. And it really motivates me every day to come back in the lab and, and try to make that next discovery.

Sarah Beatty (49:52):

And one of the things that we try to do with hope, with answers is make sure that we're asking sort of, of the moment questions about research that's happening or discoveries that have, that have just come out. Or even we try to do things like what's a biomarker and what is a targeted therapy and what are clinical trials and how do they work? Because we're trying to think what are the questions that somebody might have coming into the lung cancer space for the first time. Alice Berger is absolutely fascinating to talk to you about lung research and what I love about her, in addition to her astounding scientific work. 'cause she's just,

Diane Mulligan (50:34):

She is astounding.

Sarah Beatty (50:35):

Yeah, she's amazing. She feels such a kinship and a connection to the lung cancer patients that we work with. She's young, you know, she has young children.

Diane Mulligan (50:47):

She does, she has all those little ones.

Sarah Beatty (50:48):

Yeah. And so many of our patient advocates are young women with children, little children still at home. And Alice and I talked about how she really feels that connection and it helps drive home to her the importance of research in the lung cancer experience

Diane Mulligan (51:10):

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 lcf america.org and clicking on the donate button. What a packed show today.

Sarah Beatty (51:36):

Oh my gosh.

Diane Mulligan (51:37):

Many thanks to lung cancer patient advocate, Jill Feldman, manners and civility expert Steven Petro and lung cancer researcher Alice Berger.

Sarah Beatty (51:47):

It was absolutely fascinating to talk to all of these people and they are truly helping to bring hope into what it means to be living with lung cancer. Thank you for listening to this podcast. We hope you will join us next time on The Hope With Answers Living with Lung Cancer Podcast.

Diane Mulligan (52:07):

The Hope with Answers Living with Lung Cancer Podcast is produced by the Lung Cancer Foundation of America. Find more information online@lcamerica.org. Thanks for listening.