

## EGFR Biomarker Community: Hope Living With Lung Cancer

**Diane Mulligan:** Of all the emotions that come with a lung cancer diagnosis, loneliness might be one of the toughest. How do you find a group of people who truly understand what you're going through? I'm Diane Mulligan.

**Sarah Beatty:** And I'm Sarah Beatty. Today on the Hope With Answers: Living With Lung Cancer Podcast, you'll hear from two people who are living with EGFR lung cancer, and you'll find out how they're working together to provide education and support to others who are living with the same biomarker.

**Jill Feldman:** It is just as important to find that support and those connections. And so it changed my world. No amount of therapy could have helped me through the losses like connecting with other people who understood.

**Diane Mulligan:** Lung cancer is a tough topic. It's a disease that affects patients, families, friends, coworkers, but first, it's a disease that affects people. The Hope With Answers: Living With Lung Cancer Podcast brings you stories about people living, truly living with lung cancer. The researchers dedicated to find a new breakthrough treatments and others who are working to bring hope into the lung cancer experience.

**Sarah Beatty:** Diane, we are so lucky to work with patient advocates like Jill Feldman and Ivy Elkins. They are working hard to level the playing field for people living with EGFR lung cancer, making sure that everyone has access to the best treatments and information. But more than that, they're building a network of support for people living with the same type of lung cancer they have.

**Diane Mulligan:** Sarah, I talked to Jill and Ivy about their work on behalf of people living with EGFR lung cancer and how they're working to make it easier through education and research and why they say there's just no substitute for someone who knows exactly what you're going through.

Jill and Ivy, it's so nice to see you. And the two of you have been living with lung cancer for quite a while. I'd love for you to talk about the experience of being diagnosed with lung cancer and really what was that like. Ivy, you want to start?

**Ivy Elkins:** Sure, sure. So when I was diagnosed, it was November of 2013, and I had been, for about six months prior to my diagnosis, dealing with my neck hurting and my elbow being stiff and painful. And no one really knew what it was and no one, even including myself, was initially concerned. I went to my primary care physician, did some physical therapy, but things weren't improving. And I went to orthopedist for cortisone shots in my elbow, which was the big area of

concern. And I even went to a rheumatologist, but no one could really figure out what was happening. But I certainly didn't think that it was going to end up being lung cancer. So when I finally had an MRI done of my elbow and they found a mass that had eaten away at the bone, I still didn't think that that was lung cancer.

I thought it could be a benign growth or it could be some sort of primary bone cancer, but low and behold, after having a biopsy and further tests - PET scan, CT scan, it turned out that I had stage four lung cancer that had spread to my bones. And also in my brain, I had eight small, very small lesions in my brain. So to say that I was shocked is an understatement because at that point in my life, I was 47, very healthy, active. I mean, I had no idea that I could even be diagnosed with lung cancer. I didn't think I had any risk factors. I didn't know at that point what I know now, which is that anyone with lungs could get lung cancer. I was and my family, we were all just devastated and shocked when I was diagnosed.

Diane Mulligan: Well, I'm sure you were and the family too. And for Jill, it's kind of the opposite for you because you have such a family history.

Jill Feldman: Yeah. And I mean, most of my whole life revolved around lung cancer, having lost my dad when I was 13 and a couple grandparents, and then my mom and my aunt when I was in my twenties. So I had known that I could get lung cancer, but when I was actually diagnosed, I felt differently. And so when my mom was diagnosed with lung cancer is when I started getting periodic CT scans. And my first couple of scans I would do every three years, they were okay. And then there was something found on a scan and we watched it for three and a half years. And I'll never forget the appointment. I was at a pulmonologist appointment for my brother who has COPD, and I had the pulmonologist look at my scan. So when he came back in the room and said my scan looked ominous, I was speechless. Literally, he said, "Are you okay, Jill?" And I said, "Yeah." I just never expected it to be me. I had been preparing myself that my brother would get lung cancer because he had COPD.

So that, I was 39 years old and it was in 2009. And I had four small kids whose only association with the disease was death in my family and actually a few friends. And so they were scared. And my biggest fear was becoming a reality. I was following in my family's footsteps. And at first, I was diagnosed stage one. And so I'm like, okay, I'll take one for the team. I'll use this in advocacy. But then when the cancer kept coming back and my prognosis changed and I was stage 4A, it was contained to my chest back in 2012, 13, I was terrified because there wasn't any promising research at the time to convince me that my path would be different than my parents. And as far as my family, I mean, how many times

does one family have to hear again and again, it's lung cancer. So it really was more devastating than I imagined it would be because of my intimacy with the disease before. It puts it in a whole different perspective. And when your emotions are involved, it's a completely different ball game.

**Diane Mulligan:** Absolutely. Now the two of you have worked together as advocates for a long time. I want to know what does it mean to be able to connect with other people who are also living with lung cancer, and how do these connections really help you in your own life?

**Ivy Elkins:** Really incredibly helpful. When I was diagnosed, actually the first person I met was Jill. At the time, she just lived 10 minutes away from me. We had several mutual friends, but we had never actually met. And she pretty much gave me on the phone a crash course, and it was lung cancer 101, and told me all of the things that I needed to know, things that I should ask my doctor, even helped me change my appointment to a different thoracic oncologist who she thought would be better for my situation who I actually adore and have been with since I was first diagnosed, so almost eight years. So it was tremendous to have someone to talk to who was also living with lung cancer. I also had young kids when I was diagnosed. And we talked about all kinds of things, including what to tell the kids, how to tell the kids, just everything.

And it has been helpful throughout my time living with lung cancer. I don't think you can underestimate how alone someone might feel when they're diagnosed and not knowing the language and terminology. And meeting someone who understands what you're going through, whether it's someone close by, like Jill and I are physically, or whether it's online through a patient group, like the EGFR Resisters, is just an incredible way to connect and feel like you're not alone, that you have people who can really, really understand.

**Jill Feldman:** Yeah. And again, it was different and there really aren't words to explain the feeling of helplessness that I felt when I watched my mom and dad and aunt be diagnosed, suffer and die from lung cancer. There wasn't any support. There was no compassion. People didn't understand the disease. There weren't any grassroots lung cancer walks or events anywhere in the country. And there certainly wasn't a lung cancer community. And so for me, it was coincidence or fate, but the first organization in the country dedicated exclusively to lung cancer was founded in my community, and I got involved. And I wasn't a patient, but even as a loved one or a caregiver, it is just as important to find that support and those connections. And so it changed my world. No amount of therapy could have helped me through the losses like connecting with other people who understood. And then when it came full circle and I was diagnosed, it also armed me with a lot of information and knowledge. So that was helpful.

But more importantly for me, I knew that my kids also would never have to suffer in silence like I did.

Diane Mulligan: So is that one of the reasons why you started the EGFR Resisters group?

Ivy Elkins: Yes. We started the EGFR Resisters groups for a number of reasons. I mean, we wanted patients to have others who they can connect with. While we are in the Chicago area, a major city, and there are a number of people living with lung cancer, people get diagnosed everywhere. And in some smaller communities, they might not know another person with lung cancer. They might never have connected with someone. So having these online communities is so important for people to get support and gain education from each other and from some of the events and webinars we put on through the community. There's a lot of things that you can learn through being part of one of these patient communities, like information about new treatments and clinical trials.

I mean, if there's something that you are considering as a patient going on in terms of a treatment, there's nothing better than being able to reach out to the community and say, "Hey, how is this going for you? What's been your experience? What side effects are you dealing with? How are you handling these side effects?" It's really an incredible resource. But I do have to say one of the other reasons why we created the EGFR Resisters is because we also recognize that there's a desperate need for increased lung cancer research. And while we've made a lot of strides, there's still a lot more to be made, and we really want to get to the point where EGFR lung cancer can be treated like a chronic disease. So through the force of our community, we've done a lot of work in creating partnerships with other advocacy groups, with industry, with different organizations in order to come up with ways to accelerate research. And that was really important to us when we started the group.

Diane Mulligan: I love the part about accelerating research, but Jill, what are some of the other reasons that you joined with other groups like the LCFA group?

Jill Feldman: Well, I think Ivy did a great job of covering about the EGFR Resisters. I do want to add to that though that it's just as helpful for loved ones or caregivers to join the group and to be able to have someone to connect with, because that is a whole different set of uncertainty and worries that only those who have the lived experience can understand. But I think what I love about the group and connecting with other organizations like LCFA is that we are better together. Working together, collaborations are key to advancing anything, to advancing research, to advancing support, to make advancing connections between researchers and patients. And so I think when you work alone in a silo, nothing can be accomplished that's going to really provoke systemic change, but when

you collaborate like the way we do, it's really gaining different insights because no one person or one organization has all the answers. And when we challenge each other to think critically, that's when the best ideas, the best outcomes happen.

Diane Mulligan: Absolutely. And Jill, you've been living with lung cancer for a long time. How many years now?

Jill Feldman: Well, tomorrow, it will be 13.

Diane Mulligan: Wow. That's outstanding. Not outstanding that you have lung cancer, but outstanding that you've been living with lung cancer for that long, and that's really good. And you've been able to see some incredible changes in treatments. Can you talk about how the discovery of the EGFR mutation and its sub-mutations have made a difference in your treatment?

Jill Feldman: Oh, yes. Yeah. When I first got involved in advocacy, the only distinctions doctors could make was whether you had small cell or non-small cell lung cancer in 2001, and you had three treatment options: chemotherapy, surgery, or radiation. And often the treatment and the side effects that came with it were worse than the cancer itself, and really the benefit was marginal. I mean, that was the world that my parents, when they were diagnosed. So when the whole EGFR was discovered, and that was back... Well, it was discovered in the early 2000s is when it was started, was being talked about within the community.

It wasn't until 2013 that the first treatment was approved as first line therapy. So it really took a decade, more than a decade to discover this gene and then understand it, understand the biology of it and figure out how to treat it. But if you look at the past five years, the advancements in research have galvanized the community with the number of therapeutic options and the different indications where they can be used. It has literally just the been... It's been like a tsunami came in in a good way and just changed it, changed the entire landscape. And so it makes it more complex and complicated than it was before where you don't just test for non-small cell or small cell. There's all these different mutations, but as research advances and as we learn more, we're seeing that really lung cancer is not one disease and that there are very different treatments depending on the type that you have. And getting those treatments, getting the right treatment for the type of cancer you have is life-saving.

I mean, that makes a difference in life expectancy. My dad died three months after he was diagnosed with lung cancer. My mom died six months after she

was diagnosed. When you look at someone like Ivy, who has lived eight years since she was diagnosed, that is the difference in these biomarkers that are being discovered and how people are treated. And it's amazing, and it's really, really been exciting, but we still have a long way to go. And so it really is now for me and I think for a lot of people, it's balancing that hope with urgency.

Diane Mulligan: I think you're absolutely right. I mean, I'm interested for you. Tell us about how where you lived has impacted your access to care.

Ivy Elkins: So I live just outside of Chicago and because of that, I have been really fortunate in accessing care because there are major academic medical centers, both University of Chicago and Northwestern in addition to others, that are very close by to me, but that isn't necessarily the same everywhere. And in fact, I'm more in the minority of people being diagnosed with lung cancer in that there are experts right where I live, who's expert, fantastic knowledge leaders in oncology and in particular thoracic oncology and clinical trials and great surgeons, but it really is a problem that treatment for lung cancer, and not only treatment, screening, diagnosis, everything really, really varies or can vary depending on so many different things. It could be geography, where you live. It could be other determinants of health equity, whether it's racial, socioeconomic, ethnic, age, so many different things.

So I consider myself extremely fortunate being diagnosed and living where I am and having the abilities financially to access treatment. Again, it's not the same for everyone. And one of the things that we have tried to do with the EGFR Resisters is to reach people who are not necessarily at these major academic medical centers, who are being treated in community centers, where they might have an oncologist who treats all different kinds of cancer, and because the field's changing so rapidly, might not know about the latest treatments and clinical trials. And that's what we can share with other members of the community. However, we still know that we are not reaching everyone. There is still people who might have issues with technology who we can't reach, or may have just issues with connecting because they might feel that our group might not be representative of their experience and they are not comfortable connecting with us. So it's a challenge and it's something that's going to take really everyone in the lung cancer community working together and working hard to overcome, because personally, I would love to see a world where everyone who is diagnosed with lung cancer has the same access and the same possibility for treatment as everyone else.

Diane Mulligan: And it's so true. I mean, Jill, you were talking about we still have so much, so far to go when it comes to treatment and to dealing with the cancer. And Ivy, the access is another issue where we have so far to go. So while we've made

fantastic strides, we still have quite a bit to do. And I'm so glad you ladies are out there working on that. So, Jill, last question. Many people have said that a cancer diagnosis is a gift. Personally, I don't know anyone who said that, but I know that there are people out there. You say it's a gift you'd like to return. So I want to know how does humor help you when you're diagnosed with lung cancer?

Jill Feldman:

Yeah, so it is. I do say I would've returned it a long time ago had it been a gift. So people do say that a lot, and I choose to kind of say, I look at silver linings, but humor is such a big part of coping and what our family uses. And we always have used it. I mean even with my parents. And actually when I was younger, I didn't think it was so funny, but as I got older, I realized it was a coping mechanism and that it really kind of allows also, it kind of gets the elephant out of the room. It allows whether you're just with family or my kids or friends, it kind of just takes that kind of nervousness out of the air where people can talk about it, can talk about the lung cancer without it having to be everything scary or negative about it.

And I was just telling someone the other day, and I can't even remember what it was that I was on, but that I always shower and I always put on makeup and do my hair for my doctor's appointments because I want to look like I'm worth saving. And so it's like using those little kind of jokes just kind of lightens the mood. And I think sometimes, it takes people a while to get there, and some people aren't comfortable with it, and that's okay if I have one friend that is not comfortable with the joking. But actually what I do is I think I do it even more around her. And then she gets that half "Ugh!" where she makes the face, but she kind of giggles. But that's just, it's real. It's part of life, my life, like anything else in my life is. And humor helps with everything. And so I have always used it.

Diane Mulligan:

What a great way to end this part of the podcast. Where can people find EGFR Resisters?

Ivy Elkins:

There is a number of places they can go. We have a website, [egfrcancer.org](http://egfrcancer.org), and that is a great place to go to read about all of our programs and everything that we offer. And anyone can sign up. We have a monthly newsletter that we send out. So anyone can sign up on our website to receive our monthly newsletter. Now patients and caregivers can also access our closed Facebook group where they can answer just a few questions and join. And the reason that that's only available to patients and caregivers is that we want them to be very comfortable with sharing things that are personal to them that they might not want to have other people know about, to be honest. And then we also have a good presence on social media, both on Twitter and on Instagram. So there's a lot of places where you can go to learn more about us.

Diane Mulligan: Well, I'm sure that our listeners and our viewers are going to do just that because who wouldn't want to know more about the two of you? I know every time I'm with you, I learn more and I just love it. So thanks so much for talking with us today.

Jill Feldman: Thank you, Diane.

Diane Mulligan: It's amazing how quickly things are changing in the landscape of lung cancer. From Jill's experience of having no one to talk to, to Jill and Ivy's work, now with so many people who are living their lives while also living with EGFR lung cancer. We are so grateful to Jill Feldman and Ivy Elkins for taking the time to talk to us.

Sarah Beatty: And if you are enjoying the Hope With Answers: Living With Lung Cancer Podcast, consider making a donation to help LCFA produce this resource for patients or anyone seeking answers, hope, and access to updated treatment information, scientific investigation and clinical trials. It's really easy on your cell phone, just text "LCFA" to 41444 to join in this important fight. Thanks for listening.

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