

The PD-L1 Biomarker: A Lung Cancer Survivor's Guide

Transcript

Jane Perlmutter (00:00):

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James Hiter (00:19):

Living with lung cancer, ask me anything. Real conversations with people living with lung cancer. Learn from their personal journeys and expert insights. Subscribe now and never miss an episode. Welcome to Living with Lung Cancer, Ask Me Anything. I'm James Hiter and I'm living with lung cancer. In this episode, we're talking about PD-L1. It's one of the most important biomarkers in lung cancer today, yet many patients have never heard of it until after they're diagnosed. So let's find out what PD-L1 is and why understanding it could help you make more informed decisions about your treatment. Joining me today is fellow Lung Cancer Foundation of America Speakers Bureau member, Jane Perlmutter. Today, she's gonna help us understand one of the most important biomarkers in lung cancer, PD-L1. Jane, it's so good to have you here. Thanks for joining.

Jane Perlmutter (01:13):

Thank you so much for inviting me. It's always great to see you, and I'm always happy to share my story and help more people learn about lung cancer.

James Hiter (01:21):

Yeah, thanks. Well, it's always a fun time when I get together with you and, um, you know, you're, you're kind of a seasoned professional when it comes to advocacy and your knowledge of cancer. So, um, I, I wanna, before we jump into PD-L1 though, I wanna ask you just to share with the audience a little bit more about your cancer story, your background.

Jane Perlmutter (01:41):

So, um, I am a lung cancer survivor now, um, and I've been living with it for about four years. But my cancer journey started way before, more than 40 years ago when I was, uh, in my early 30s, I was diagnosed with, um, uh, breast cancer. And since then I've had other cancers, but I'm still here and doing great. And in, during this time, I've actually gotten involved in a fair amount of advocacy work, uh, dealing, helping other patients who are diagnosed and also learning a lot about the research and working with researchers.

James Hiter (02:13):

Uh, fantastic. It's one of the reasons why I really was excited about you on this topic in particular because I know you have a lot of technical knowledge on top of just the lived experience o- of lung cancer. So can you recall kind of when you first learned about this concept of PD-L1?

Jane Perlmutter (02:31):

Well, because I've been involved in cancer research in general, I heard about it, um, about 12 or 15 years ago when it was first, um, discovered that, uh, some certain drugs help patients that had PD-L1, um, and



it was approved in melanoma. Um, and since then it's been approved, uh, people are being tested for PD-L1 and there are drugs against it, uh, for many, many, many cancers, including myself.

James Hiter (03:00):

Can you help folks ex - understand exactly what is, kind of in layman's terms, what is PD-L1?

Jane Perlmutter (03:05):

Right. So cancer in general is when something goes awry in some cell and it reproduces very rapidly. This happens fairly often in our bodies, but our immune system often protects us against it. It finds something wrong and it chews up those cells, if you will. Um, some cancer cells though, uh, try to get away from the, um, immune system and they put out this PD-L1 which says to the immune system, "Don't get me, don't get me." And if there's a lot of that PD-L1, the immune system doesn't get rid of the cancer and, uh, that's what's the problem.

James Hiter (03:43):

Yeah. I, I kind of think about PD-L1 as like camouflage on the cancer. So if you, you think about a battle and, you know, your immune system's trying to go get the bad guys and the bad guys have this layer of camouflage over them, that's that PD-L1, uh, on the cells that make it harder for the immune system and know that they're even there or that they need to get them. Uh,

Jane Perlmutter (04:04):

That, that's such a great metaphor. I'm sorry I didn't think of it. <laugh>

James Hiter (04:07):

Well, so PD-L1 though is not the entire story. It's just part of the part, part of it. We, we talk sometimes about all the locks that we have to unlock to really get an effective treatment, PD-L1 being one of those locks. Can you talk about PD-L1 and biomarkers?

Jane Perlmutter (04:24):

Uh, yeah. Um, I don't know. 15 or 20 years ago, we started recognizing that every cancer is unique and, uh, basically there's different things that go wrong in these cells and there are ways that we can measure what exactly is going wrong. And then when we discover something that is wrong with the cell, we can find a treatment to, uh, p - get rid of that. And there are now lots and lots of different, um, biomarkers that is things within the cell that go wrong that we have drugs against. And that's really one of the reasons why so many people are now being able to live a long life with lung cancer because some of those drugs help. But it's really important to get as much information about the individual cancer because there are so many different ones. Um, you may have heard of EGFR or ALK or ROS1.

(05:15):

All of those are biomarkers that some lung cancer patients have within their cells, and we have treatments against them. So getting really to know as much about the particular cancer that you have will help doctors give you the right treatment.

James Hiter (05:31):

Every week on the Living with Lung Cancer, Ask Me Anything podcast, we explore the questions that matter most to people living with lung cancer. We talk about new treatments, everyday challenges, breakthroughs in research, and the stories of patients and caregivers finding strength and hope. If you want these insights delivered straight to you, subscribe on any podcast platform or go to lcfamerica.org.



And if you know someone who could benefit from understanding and encouragement, share the show with them and don't forget to subscribe. Now, let's get back to our conversation. If the treatment is the key, it's got to go in the right lock. Right. Um, and so that biomarker testing really helps us identify what is the lock and then which key can we use to, to kind of unlock it. Right.

Jane Perlmutter (06:18):

And one of the things about PD-L1 is that that actually is a little bit different in that, um, it actually releases your immune, own immune system. Many of the others that I've mentioned, um, actually it's something within the cell and we have a targeted therapy that will, uh, target that, um, mutation in the cell and, and kill it so that we talk about immune therapies versus targeted therapies.

James Hiter (06:43):

That's helpful, uh, because they're not the same and, and both are important though.

Jane Perlmutter (06:47):

Right.

James Hiter (06:48):

Yeah. Um, w- when should a patient, um, ask their physician or their care team about PD-L1?

Jane Perlmutter (06:56):

Um, as soon as there's a diagnosis. Usually when you first have a, um, biopsy, uh, the tissue goes to a pathologist who will analyze it. And the more, uh, detail that they find about your tissue, the better they can identify what to do, what kind of treatment is best. And, um, m- most doctors recognize this and will immediately have, um, your tissue, uh, analyzed, but it's important to ask. And, um, there are different kinds of tests that are done, and sometime they don't do a complete test, but what's called next gen sequencing a- a - NGS gives you a really complete, um, uh, knowledge. And that's actually very useful and it's worth asking your doctor whether they actually got the most complete, um, analysis of your, um, cancer. Because there are a lot of drugs that are specifically for lung cancer, um, based on what you have, but there's also sometime drugs that maybe, um, we know help out other cancers, but are very rare in lung cancer, and they might be appropriate, or there might be a clinical trial you could be on.

(08:06):

So getting as good a analysis of your, uh, biomarkers is, is really important.

James Hiter (08:12):

Yeah. That's great advice. Um, do you have some concept of how long it takes to get a PD-L1 response back to the test results?

Jane Perlmutter (08:21):

Yeah. Uh, usually it'll take a week, sometime a little more, sometime a little less. And that's very frustrating to patients. You know, once you hear that you have cancer, you almost surely wanna get rid of it as soon as possible. You want treatment as soon as possible. Um, but it's really probably not the, uh, best response. Um, it's important to give yourself time to, number one, process the fact that you have this traumatic diagnosis, but even more important, to make sure that you get the right first treatment. Um, some, uh, some treatments are actually appropriate for some cancers, but really not appropriate for others. And the more we know about your particular cancer, the better chance of success and the, and having to change in the middle is sometime counterproductive.



James Hiter (09:09):

Yeah. I, I think you touch on something. I know when I was diagnosed, I wanted immediate action and I wanted to do as much as we could do, throw the kitchen sink at it, whatever. Um, but really it's important to push pause at the beginning and get the game plan nailed down before you just jump into treatment. Uh,

Jane Perlmutter (09:30):

Uh, that's exactly true. And it's also one of the hardest time, the hardest time for any new cancer patient. Um, u- until you really know what's happening, it's just ver - it is very traumatic. Once you know, even if it's not what you hoped, it's, it's actually easier. And the other reason it's important, not only to get the right treatment, but also to avoid treatments that are not right. Um, and the, getting your biomarker testing can really help you with that.

James Hiter (09:59):

Right. Yeah. I mean, back to the key in the lock analogy. Imagine j- jamming, jamming the wrong key or the key into the wrong lock, and no matter how, what you do, it's not gonna open that lock, and you might damage something in the process. And in our case, there's a chance you could, um, disqualify yourself from a, from a clinical trial or, or other things.

Jane Perlmutter (10:19):

Right. And actually sometime maybe even do more harm than good and waste time. So you've actually, um, delayed getting the right treatment. So it's, it's what, it's, it's important to get fully, um, biomarker testing and then to, uh, u- use the results. Yeah. And ask your doctor lots of questions about the results, what they mean, um, why he's picking, he or she is su- suggesting one treatment or another.

James Hiter (10:45):

Right. You know, one thing that's kind of surprising to a lot of patients, I think, is the fact that if you have very high PD-L1, uh, levels, that you might actually qualify for immunotherapy for an immune checkpoint inhibitor without chemo. Can you talk about that a little?

Jane Perlmutter (11:02):

Uh, right. Um, you know, again, different cancers are different, and PD-L1 is an indication that probably, that immune therapy is likely to be helpful to you. But, um, many patients, not enough, and therefore they give it with chemotherapy. If your cancer looks very aggressive, they may well say, "Let's start adding, having some chemotherapy. We could maybe drop that off later." Um, and PD-L1 goes from zero to 100, that's the way they rate it. And typically, if it's over 50, you have a very good chance of responding well, and perhaps you might not need chemotherapy. If it's, um, zero, it's very unlikely that immune therapy will help you at all, and you probably would not be even offered it, and they'll give you something else, maybe just chemo. If it's, um, maybe between 10 and 50, it's an if and if story - uh-huh. And, um, you may actually, the doctor might recommend having chemo plus the immune therapy.

(12:04):

Now, some doctors like to really be very aggressive, and some patients like to do everything they possibly can, and others would rather say, "Let me try and see if this is gonna work, um, with less, uh, potential side effects." So that's sort of an individual discussion that you should really have with your doctor.



James Hiter (12:23):

Yeah. Yeah, but I mean, back to our camouflage metaphor, uh, the idea of, um, if you have something magical on the battlefield that would remove all the, the camouflage to make the soldiers easier to find or make. If there's no camouflage, then that magical thing to get rid of the camouflage is not gonna really help much. So when you think about PD-L1 or checkpoint inhibitors, it's really to remove that camouflage, but if your camouflage level's really low, it might not help you as much.

Jane Perlmutter (12:53):

Right. I mean, that's definitely correct, and the, um, metaphor is very useful. But, you know, we don't know everything, and it's not only what's in your cancer, but it's also how your immune system is working. So, um, you know, PD-L1 is a really good indicator of how likely you are to respond, but it's not perfect. And people with very high still might not get a benefit, and people with very low might get a benefit. Uh, it turns out that, um, uh, when I had esophageal cancer, I also was tested, and I had very high PD-L1, and it worked great. With my lung cancer, it turned out my PD-L1 was only 20%, but I still got a total response from just a, a, an inhibitor for PD-L1. So you just really never know. Every patient is unique, and we know a lot, but there's a lot we don't know.

(13:45):

That's

James Hiter (13:45):

Such solid advice and, and good encouragement too, because I think people shouldn't be discouraged whether their PD-L1 number is high or low. There are other treatment options, there are things out there, but it also doesn't mean it's not gonna work. In your case, 20% or a t - a score of 20 on your PD-L1. Uh, you know, there would be a lot of people who would think probably immune, uh, checkpoint inhibitor is not gonna help you as much, and yet you had a fantastic response.

Jane Perlmutter (14:10):

Right. And in part, b - maybe I was more encouraged because I had to my previous cancer, but every patient is unique, and it's important to have hope and recognize there are so many people that are surviving lung cancer now and living long and good lives. And, um, what we hope is that, uh, even if the first drug that you try maybe is not as successful as you would like, by the time you need something else, there's a lot of research going on, and there are new things coming on all the time, and that's sort of one of the e- encouraging, uh, things about lung cancer. Um, and there are clinical trials that is something else that you should ask your doctor about.

James Hiter (14:49):

I was gonna ask you actually a question about, like, if you could go back in time or. Is there something that you wished you had asked about either PD-L1 or, um, biomarkers earlier in your lung cancer jour - or in your cancer journey?

Jane Perlmutter (15:04):

Well, you know, uh, uh, even with my experience, it's so traumatic, it's hard to keep track of everything. And one of my first biopsies had just a little bit of information, but it didn't have the full non, um, next-gen sequencing, and it was only after the fact that we went and got that. So I would encourage people to ask that. But, um, the- the- the other thing is, do things like bring someone with you, think about your questions beforehand, um, make the doctor stop and talk to you and- and raise issues that



are important to you. No question is- is foolish, and your feelings are really important. Help the doctor understand your priorities and, um, ask again and again. And the other thing I would wanna say is don't hesitate to get a second opinion. Um, any good doctor will be happy to have you have a second opinion, and especially if it's a- a little bit of an ambiguous case, getting a second opinion is helping the doctor, is helping you, and is something that is certainly worth doing if- if you have any question at all.

James Hiter (16:11):

So you kinda just touched on this, but are there any, you know, must-ask questions that you would say for somebody who's newly diagnosed?

Jane Perlmutter (16:19):

W- what are you doing and why? You know, first, definitely ask about getting biomarker tests. Then what do you recommend and why? And maybe what are my other options? Um, and, um, learn as much as you can. Uh, it's hard to remember it. Bring that person along to take notes and ask again and again, and keep yourself as informed as you can be. Um, you know, it- it's very hard when you're newly diagnosed, which is why you wanna get as many resources as possible. Have some of your friends or relatives listen to this podcast and the other podcasts and check in with some of the really reputable national, um, uh, cancer advocacy groups. Um, be careful about just searching the internet for information, because there's a lot of misinformation, but a reputable, um, organization could p - help you out.

James Hiter (17:09):

Mm-hmm. <affirmative>. Now when you talk about having a conversation with a doctor, I know. I- I- I have talked to so many people who I can just hear their stomach tying up in knots because the idea that they would ask a question of their doctor or that they would question their doctor, um, is kind of a foreign concept and it- it kinda terrifying. Uh, what would you say to encourage people to engage with their physician in a helpful way? Right.

Jane Perlmutter (17:35):

Uh, it's really, really hard, but, uh, talking about it beforehand, writing down your questions, um, maybe role-playing even with somebody, and, um, recognizing that, uh, doctors seem like they're very rushed, but they do wanna be there for you, and if they really don't, um, then they're the wrong doctor. And you can fire your doctor, but the doctor can't fire you. Um, and, um, you know, if you just sort of say, "Wait a second, doc, I really need to ask these questions," um, it's really, uh, almost always works. And, um, having an advocate with you, whether it's a fa- family, friend, or somebody else, um, who is a little bit more assertive if you are uncomfortable. Um, I once went with some friends to. Who had a- a really bad cancer diagnosis. They were really intelligent people. We talked a lot beforehand, we prepared them, and when they s - were there with the doctor, they just couldn't talk.

(18:30):

And finally, I just interrupted and said, "Is it okay if I talk. Tell the doctor what you asked me beforehand?" So sometime a third party that's a little bit less emotional at the time can be really helpful.

James Hiter (18:42):

That's, uh, such a great advice. Um, yeah, I think encouraging people to speak up, um, is so important, and if, uh, you are not the person that is really gonna wanna speak up, then bringing somebody along who would speak up on your behalf. But also, uh, you know, you and I both, we've talked about becoming a student of the disease. If you come into your doctor's appointments and you've read some



reputable things or you've listened to a reputable podcast or those sorts of things, and you come in with some thoughts, I think your doctor over time is gonna be even more respectful of your position. Um, I know your doctor and mine too knows that we're probably gonna have extra questions. Uh,

Jane Perlmutter (19:24):

A- absolutely. And doctors now are very, very useful for people coming in quite knowledgeable with lots of information from the internet, and sometime they're more or less comfortable going through it. But it's your right and your responsibility to ask all those questions that you might have. And, um, sometime if the doctor is very busy or you maybe feel like this is not the person, you know, there are other, uh, people who are involved with your cancer care who could perhaps help you. There might be a nurse practitioner that has more time that's thinking more about you as a whole person instead of just your cancer. If you are getting a, um, a therapy where you have IV infusions, the in- infusion nurses are often really good people to talk to. And, um, sometime an- another person who's gone through it is a good person, but be careful with that.

(20:16):

Make sure it's a person that you respect, that's knowledgeable, and, um, that can help you. But also, remember, they're not medical people. Anything that we're talking about today, James, we're not medical people, and we know that. And whenever we talk to patients, we remind them. The bottom line is ask your doctor. We're here to help you know what to ask.

James Hiter (20:37):

Yeah, that's fantastic. Um, so I, I think I know the answer to this, but can you just share how knowing your own PD-L1, knowing your biomarkers has helped you be a contributor to your own care plan?

Jane Perlmutter (20:52):

Well, it narrows down the kinds of questions that I would ask. You know, um, knowing that I have PD-L1 lets me ask questions about immune therapies, and there are a lot of therapies, there are a lot of different ones now, and I can ask about them and about whether or not I should also have chemo and things like that. If I had a different biomarker, it would narrow down the kinds of questions I would ask. It would narrow down the kinds of things I would be looking for if I was actually studying things a little bit more. Um, so, you know, the more you know, the more helpful it is, as long as you recognize that, number one, we don't know. Nobody knows everything. It's, you know, luck of the draw. And number two, um, you're not the medical person, but the more you can ask.

(21:35):

And some people wanna know more and be more involved, some people don't, and, and that's okay. And especially when you're first diagnosed, sometime it's so, um, traumatic that you can't really, uh, process much. I remember I wanted to know about possibly going on a clinical trial, and I'm pretty sophisticated by this time. And I said to my doctor, you know, "I, I would love to know if I'm eligible for a clinical trial, but I just can't deal with trying to find one. Can you help me find one?" So, you know, ask for help and, um, get it what you need.

James Hiter (22:10):

Again, such solid advice and, and really having more of a collaborative relationship with your care team, uh, with your physician, your oncologist. Um, I. You, you never wanna have an adversarial relationship. If you're having that, you probably need a new doctor, back to your, your point earlier. Um, but getting



connected to the right people where it's. Can be more of a collaboration as it relates to PD-L1, biomarkers, and just treatment in, in general. Right.

Jane Perlmutter (22:38):

I should interrupt there. Um, the truth of the matter is I did what's called doctor shopping. When I was first diagnosed, I talked to several different doctors who I was not really comfortable. Um, and I finally found someone who I felt, um, on the one hand, really listened to me but also knew a lot and we ended up hugging. And, um, you know, you need to have someone that you can feel comfortable with that's empathetic but also very knowledgeable and that treats you as an individual because we each have different values and what's important to us is, is really important for the doctor to take into account.

James Hiter (23:13):

Yeah. So, you know, research has really, uh, changed treatment and provided so much hope. Um, the last few years have been remarkable in terms of advancement in lung cancer research and treatment. What gives you the most hope right now? Um,

Jane Perlmutter (23:31):

You know, how many advances there are. You know, the truth of the matter is it's not unlikely that my cancer is going to come back and progress, and I'm gonna need something new. And partly, I would like to say to my doctor, "Well, what are we gonna do if I progress?" But partly I know, and we've discussed this actually, we don't know what will be available then, because there's every day, there's new things that are being tested, that are being approved, and there are more and more people that need a new treatment, but that is available. And, and that's really so. That does give me hope. You know, many years ago, I actually talked to a group, um, about lung cancer, and I only spoke to. The only people in the audience were, um, children or, um, spouses of people who, who died from lung cancer.

(24:17):

Now, I have all these friends who are living with lung cancer and living, um, relatively good lives, and that's what gives me hope and encouragement. That's

James Hiter (24:26):

Awesome. Um, what final advice do you have for anybody who would be listening to today's podcast, whether it's about PD-L1 or just in general? Right.

Jane Perlmutter (24:36):

Um, uh, first of all, good luck and have hope. And second of all, know that that hope is not, uh, you know, there's no guarantees, but it's not false hope either. There's a lot out there now, and, um, there's always more. And the other thing is, although, um, having metastatic, uh, lung cancer is a terminal disease, we just never know. You know, uh, what I, uh, learned after my first cancer is conception is really our death sentence. We all have one, um, and we never know when it will be. Um, live this life as well as you can every single day.

James Hiter (25:15):

Outstanding. Such great advice. You know, we're. I say we're all terminal. Some of us are just more aware. Right.

Jane Perlmutter (25:21):

Um,



James Hiter (25:21):

So - But

Jane Perlmutter (25:22):

That does help you sometime remember to be thankful and to, um, appreciate what you do have. Yeah.

James Hiter (25:29):

Great. Jane, thank you so much for joining and for sharing your lived experience with lung cancer. Um, it's just been awesome to hang out with you. Oh,

Jane Perlmutter (25:38):

Thank you so much. I love this also. I'm gonna take a hug.

James Hiter (25:41):

Oh, absolutely. Thanks for listening to Living with Lung Cancer: Ask Me Anything. I'm James Hiter. If today's conversation was helpful, please follow or subscribe and share the episode with someone who might find it useful. Together, we can change the way that we talk about lung cancer. If there's a lung cancer related topic that you'd like for us to explore, please let us know in the comments and find more information and resources at lcfamerica.org.

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