



Small Cell Lung Cancer Subtypes: What Patients Should Ask Now

Montessa Lee (00:00):

I've also now been able to sit at the table and see what I've been waiting for, which is the birth of these new developments for small cell lung cancer.

James Hiter (00:08):

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 and I'm living with lung cancer. For years, small cell lung cancer has had far fewer treatment options than other forms of lung cancer, but that's changing. New immunotherapies, targeted treatment strategies, and exciting clinical trials are creating real reason for hope. Joining me today is a fellow Lung Cancer Foundation of America Speakers Bureau member, Montessa Lee. Montessa is a long-term small cell lung cancer survivor and patient advocate. Hey, Montessa, and thank you for joining us. Um, you know, I wanna get started with our listeners getting to know you a little better. So would you mind to share with us a little bit about your really remarkable story with, uh, small cell lung cancer?

Montessa Lee (01:10):

In 2006, when I was 28 years old, after two misdiagnosis, um, I was diagnosed with small cell lung cancer. Pain in my chest wouldn't go away and a cough, you know, all of the symptoms, if you read about lung cancer, I had, but I was 28. So I went to the doctor. They, first time they said, "Oh, you have inflammation around the rib cage." Sent me home with ibuprofen. Second time, "Oh, you have bronchitis." Third time, they finally did an x-ray. And that x-ray would reveal that I had a tumor the size of a cantaloupe.

James Hiter (01:40):

I want to acknowledge how unusual your story is, and I say that with a heavy heart because that, there aren't many small cell lung cancer survivors that have had your experience, but how amazing that you have. And, and I just wanna say how grateful I am that you have taken your life, your time, and are using it for advocacy for the amazing research that I'm excited to talk to you about today.

Montessa Lee (02:06):

At that time, lung cancer period, you know, we were advocating for and I looked at the numbers and I was angered, you know, by the low prognosis rate, by the low funding for research. And I decided to turn that anger into advocacy.



James Hiter (02:19):

I had the opportunity to, um, be at ASCO this year and there was so, there were so many exciting developments, um, things that I was knowing people like you and other friends and even some friends that we've lost to, to small cell that such exciting developments that, um, um, just give us so much hope. Um, can you tell us a little bit about your experience with that hope growing?

Montessa Lee (02:48):

Sure. And, and like you said, 20 years ago, this is the hope that I've been waiting for, you know? Yeah. 20 years ago, well, 20 years, it'll be 20 years in December. And now we're hitting the cusp of what I've been waiting for. When I sat at the table and I saw growth in non-small cell lung cancer, and I knew that, I said, "There's gotta be hope on the horizon for small cell lung cancer." And just, you know, it wasn't until 2019 we had another breakthrough of medic- medicine, but now in the recent years, like you talked about in going to ASCO, you probably saw several poster sessions on small cell alone. So just the rapid development, um, that they're providing treatment options being plural and, and looking at a patient as being more individualized. I'm, I'm hopeful. I'm very excited about this.

James Hiter (03:34):

Yeah. And, and it's almost like it's exponential growth in this field that, that the, that just keeps accelerating.

Montessa Lee (03:41):

You're right. I, I agree with you. Um, just like, you know, in comparing it with what you knew before, the non-small cell, small cell now, like I, we can't keep up. 2019, we see developments, we see new drug approvals, FDA approvals for drugs. We see research after research, different labs studying small cell. And he, case in point, we'll go to the summits that are specifically focused on small cell lung cancer. Last year we went to a lab. This year we went to a lab and there's more research. Things have changed. And so you just imagine like in the course of six months, nine months, like what's gonna come down the pike next?

James Hiter (04:19):

Yeah. I enjoy hearing stories from people like, uh, Lung Cancer Foundation of America's founder, Kim, who talks about, you know, her first trip to, I think it was ASCO where there were, you know, a handful of people in a room. And then you fast forward and then it's so much focused on lung cancer versus all the other cancers. I mean, we still have a ways to go. Uh, the funding is still way far behind, but amazing advancements. And now, uh, you know, you start to crack the code, um, and, and you get to see those advancements.

Montessa Lee (04:51):

Right. And I, and I don't want us, like you said, to lose the momentum because we've come a far away, but there's still a far away to come - Yeah. To go, you know, and we're on that way, you know. So we're,



we're at the cusp, you know, we're, you know, you think about a marathon race, maybe we're, what, a third of the way in? We're still running it.

James Hiter (05:09):

We got more to go, but wow, how exciting it is to know that some things are starting to fall in place.

Montessa Lee (05:14):

Right. And I think, you know, it's opening for the people. Thank God for the people in research and those that are focused on small cell, because it took one of those researchers years ago, I was at a talk talking specifically about small cell, and I was, um, giving a speech about forget us not, you know, and, and talking about the exponential growth at that time that non-small cell had and how we hadn't caught up. And until she sat down with me and explained the disease, I said, "Wow, it's almost a totally different disease than non-small cell." No one had ever opened my eyes to that, even being in years of advocacy and, and in this world sitting with scientists and, and going to these conferences bec - number one, because I didn't see a lot of studies for small cell either, but just understanding how hard of a disease it is to treat and now to see all of these new options and the, the people are still studying new options.

(06:07):

So I'm excited for you.

James Hiter (06:08):

Yeah. I, I think that was one really big misconception I had when I was first diagnosed. I think I just thought you had lung cancer. So lung cancer is lung cancer. And then you're like, "Wait a minute, there's small cell, non-small cell." And then you're like, "Wait a minute, in non-small cell, we have all of these subtypes - uh-huh. And these oncogene groups." And, um, each one of those is almost like its own unique thing where the medicine that targets one doesn't necessarily even begin to work in another, but yet those advancements help us figure out the other. And I feel like that same thing now is happening with small cell. Can you talk a little bit about subtyping?

Montessa Lee (06:45):

Sure. And, and they have come to the development of, they know there's different subtypes. We're not, we're, we're not small cell. The world of small cell's not where it is for non-small cell yet where it's treated as an oncogene group or targeted treatment option yet, but we're getting there, you know, and, and, and, and that's a big, I think, development with those subtypes of small cell lung cancer. And they can look at some subtypes and say, "This treatment will probably work better, you know, if, for this subtype or this subtype." But it, we're gonna get to the point, hopefully, I think where we're gonna get some targeted treatment options specifically, and it's gonna be for everybody.

James Hiter (07:22):

Yeah. I mean, it's exciting. I mean, when you think about, again, back to the deal, you, the same keys that open one lock don't open another lock. Mm-hmm. And so you've gotta first i- identify the different locks.



Montessa Lee (07:33):

Yes.

James Hiter (07:33):

Um, and that's kinda what's happening now. It's happened with small cell - with I - non-small cell and is happening - uh-huh. Now with, with small cell.

Montessa Lee (07:43):

Right. And I relate it all back to my, you know, my, my other job <laugh> besides advocacy is I'm an educator, a special educator. And what we know about the learning profile, it's as varied as your fingerprint. And so we know the, you know, I love Little House on the Prairie, but we know the one room schoolhouse doesn't work anymore. And we know that the one size treatment option doesn't work for everyone.

James Hiter (08:04):

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. When should somebody with small cell lung cancer talk to their doctor about subtyping?

Montessa Lee (08:46):

So when you go to your doctor and you find out, you know, you're sitting at that table or you're sitting, you know, across from the doctor and they said you have small cell lung cancer, you or your caregiver can say, "I've heard about subtypes. You know, I've been attending these support groups and I know that scientists have discovered there's different subtypes. And I know that it's not always in use, but can you tell me what kind of subtype do I have? Is that possible that you could treat my tumor for that?"

James Hiter (09:15):

That's fantastic. I, I think you bring up such an important thing and I s- so many people are intimidated by their doctor or they don't wanna upset their doctor wh - by asking for a second opinion or by suggesting something. I, I think especially if you're being treated in a rural health setting, you need to understand that your research, your help is actually helpful to the doctor because they can't be an expert at everything. Um, and so asking these questions will cause some things to happen that should be really positive actually for your, your care.

Montessa Lee (09:48):



Mm-hmm. And it's quite possible that after you've worked with your care team for a while that they know you. And so you're one that co - always asks questions, "Hey, I've been reading these articles. I've been watching the news and I know that this level of treatment has come out. This is what it's saying. Is that possible for me?" They might know you by then, you know. Absolutely. And if you can't answer those que - ask those questions, I always suggest to new patients to have a caregiver with them or someone who could retain some of that information. Mm-hmm.

James Hiter (10:18):

So important. Um, a- a- anybody who's a frequent listener of these podcasts knows that I al- always advocate for being a student of the disease, especially being a student of your variation of this broader lung cancer disease. Um, and the more you get to know, uh, the more you can contribute to that conversation with your care team. As a patient, why is it good to understand that small cell lung cancer can change?

Montessa Lee (10:45):

I think it's important because. Well, for me, I can speak for myself that that's where the breakthrough happened for me to understand that why the disease is hard to treat. And we got to understand this as a patient group. Some of us went into a lab, um, just recently, this, this past year. And, and every. We've been back at the lab probably four times and they've talked about this plasticity. And it really hit home with a lot of patients to unders - maybe some are scared, you know, it might scare them. Some to say, "Hey, it's not, it's not gonna stay there. It's not stable. I don't, you know, what, what if it comes back? Or X, Y, Z. How do I know I'm treating what I have now?" But I think that knowing your own disease, like you said, knowing the disease is important and understanding why, how, how, why it's hard to treat and how we've come so far.

James Hiter (11:33):

Yeah. Well, I know my variation on the non-small cell side is also kind of wily and has been hard to treat the KRAS mutation. Um, and they're finally starting to crack the code, still working on cracking the code on my specific variation of the variation, which we're figuring out there are like subgroups of the subgroups. Um, but so important to understand that it, it can change, uh, it can evolve. And, um, I, I just heard another story of somebody who had a second biopsy and found different mutations or different things that were going on with their cancer, um, at the time of that second, you know, being able to get tissue and, and see that. Um, so when we talk about research advocacy, which I know you've been involved with a lot, um, w- we're very happy, and I wanna say, uh, that so happy to have doctors that are working on extending our lives.

(12:34):

Um, obviously we wouldn't be here if it weren't for that research and stuff that's been done. What do you say to researchers though about quality of life as we work on extending length of life?



Montessa Lee (12:48):

Sure. The quality of life is a big factor. You know, I, patients are, this is big in the patient advocacy world now too, that we're not just looking at overall survival, but how are you living while you're surviving? And whether that be, there are new treatment options that you'll probably get into later talking for small cell lung cancer, that one of the side effects that I hear a lot of people talk about is loss of taste. Now, to me, that might not be a big idea. To you, it might not be a big deal. But for some people, they might want to get off treatment just because that is a huge impact to their life because they used to love food. Now they, they can't even think about the thought of eating or it's just so impacting their life that they have to take a break.

(13:31):

Fatigue can be one, you know, where the, so talking again back to your care team, everything goes back to talking to your care team about those side effects. And again, your care team can be more than your oncologist. It can be a social worker. When we talk about treating the whole patient, we're talking about mental health, your social health, socialization, your whole body health.

James Hiter (13:53):

Yeah. No, I, I think it's really important that I, I, I, it's hard for me to put myself in the position of my oncologist or of my care team, um, because there's so much that needs, information needs to be conveyed. Mm-hmm. It's also often, at least initially, in kind of a crisis mode. So, you know, look, at, at the very first time when I'm diagnosed, I want it out of me. I want it e - I want the kitchen sink thrown at it. I want everything. It's not until later that you start to realize some of the longer term effects of some of those treatments. And it's not that I would trade my life for that. Mm-hmm. I wouldn't ask to not have longer life. Um, but certainly knowing what to expect is, is helpful.

Montessa Lee (14:40):

Right. And talking about, we were having a conversation earlier. So my initial treatment, which is different than the options people have now, but I had, um, hearing loss, you know, like first to start as denied as, you know, ringing in my ear, severe ringing in the ear, which I wouldn't have necessarily thought to tell my doctor. But I told him, oh, no, you know, I just have a lot of ringing in my ear. And he's like, whoa, you, you know, let's switch, because at that time I was on cisplatin, let's switch to another carp - uh, um, platinum-based chemotherapy carboplatin to hope rectify it and get a hearing test. But things you don't think about like that, like the radiation to my chest put me at risk for breast cancer, having to go get mammograms. You know, so there's always gonna be some level of a risk, but again, like, am I still living my quality of life?

(15:27):

Um, no, the ringing kinda irritates me some, but I've learned to overcome it. I put the captions, closed captioning on the TV. Yes.



James Hiter (15:34):

Yeah, right on. And sitting here in this studio where it's nice and quiet, I, before we even got on this topic, I could hear my ears ringing, uh, and was thinking the same thing as we're jo - launching into kinda quality of life and side effect conversation. Mm-hmm. Um, but, you know, like I said, I wouldn't, I would, I'd take all the ringing, um, to have, to get to meet my gr - new grandson who was just born two months ago. Mm-hmm. Uh, those are the things that, uh, you know, look, I'll, I'll tolerate a lot of things in order to get to those life milestones. Mm-hmm. Um, what are some life milestones that you've been able to experience as a result of your longer life as a small cell lung cancer survivor?

Montessa Lee (16:13):

Well, two things, um, I could think of right off the top of my head. When I got diagnosed, I was in the middle of my master's program, I think like we talked about. And I was on my way to my grad school class and, you know, derailed me, which I thought I didn't know if I was gonna need accommodations. My brain, I didn't know how it was gonna work coming back, but I successfully finished my, uh, my master's degree and now I have successfully finished my doctoral degree. Um, so those are two milestones. I've also now been able to sit at the table and see what I've been waiting for, which is the birth of these new developments for small cell lung cancer. And when I first started this advocacy work, I only knew about, I think one person that had small cell. Physically, I only knew per - one person that had small cell lung cancer and caregivers.

(16:59):

Now I can sit in a room and facilitate a group of survivors and caregivers. Sometimes we have more than 50 people in the room and, uh, people cannot under - I cannot explain to you how I have never witnessed that until the last few years.

James Hiter (17:14):

That's phenomenal. It's just such a, a. I've heard it, uh, called, um, yeah, u- u- unprecedented hope.

Montessa Lee (17:23):

Oh, yeah. And, and I didn't even think about that on the social media. I can't even keep up with how many people are in the, you know, the chat group that they have for small cell lung cancer. It's. Every day I see new people have joined, new people have joined. And, and, um, it's a lot to keep up with, but it's, you know, you never want anybody to enter this world that they've been diagnosed with lung cancer, but it's hopeful that they're here and they're sticking around years after.

James Hiter (17:47):

Absolutely. Well, I, I. So let's visit that for just a second, because one of the things I wanted to talk to you about was this idea of out of date statistics. So what do you say to somebody who's newly diagnosed and reading those stats on the internet from Dr. Google?



Montessa Lee (18:04):

Yep. And I, usually I tell patients, "Don't go to Dr. Google," you know, the, with the newly diagnosed patients. Do not go to AI. Well, now we have the birth of AI too. Don't go to AI or Dr. Google because things are rapidly changing. If you wanna really get any real-time information, go to the last publications from ASCO or lcfamerica.org. Um, go to any of the lung cancer groups to really get true updated information. And you might have to look every month because the, the information's rapidly changing.

James Hiter (18:36):

Yeah. And it's so true. And, um, publications coming out all the time, new work being done, treatments that used to be only done inpatient because it was so new, um, now being done outpatient like it is in non-small cell, more similarly. Uh, so many amazing inves - uh, uh, uh, uh, advancements. Um, for somebody that's newly diagnosed, what are some of those questions that they should really be asking their care team?

Montessa Lee (19:05):

So some of those questions for s - you know, if you're straight off, you know, you're sitting at the doctor's table and they say, "You've been diagnosed with, um, lung cancer." Find out if it's extensive stage or limited stage. Ask your doctor, "What is the care treatment plan? What does that look like for me? What are my options?" If you're curious, you might even ask if there's options for clinical trials. Uh, ask, "What does that treatment look like?" So if they say it's chemotherapy, what are the possible side effects of that chemotherapy? Radiation, if that's an option. What are the side effects of the radiation? How long am I gonna be in this treatment? So all of those basic questions first. Then you can, you know, ask about the side effects. Then I, um, people have encouraged me and other patients to keep a journal. So you keep a journal of those side effects that you're having, and you can talk to the doctor about those side effects that you're experiencing under treatment.

James Hiter (20:02):

Yeah. I mean, I even kept a food journal when I was, uh, having a- active chemo because I wanted to see if my body was having an, uh, you know, kind of an adverse. If, if all. Every time I ate tacos, I got extra sick. I know. I wanted to know that. So I kept a little journal of the food I was eating and, um, to make sure that I, I, I wasn't repeating a mistake that I didn't even know I was making. Um, so those are great, great, um, uh, questions and great advice. Um, when we think about where the research is heading, what excites you most about, let's say, five or 10 years from now?

Montessa Lee (20:40):

Five or 10 years from now, you know, almost. And I'm correlating it a little bit with the non-small cell lung cancer world where you have targeted treatment options. So where I'm seeing is that they're gonna possibly take the research they're doing with subtypes and, and expand that, and then they're gonna say, "James, you get a treatment specifically for you. Montessa, you get a treatment specif- specifically for you. Then we can look at long-term survivorship. Is there anything we need to do for these people that



are living for a long time and surviving?" And s. But that's my hope, is that we are gonna get to where we are even narrowing it down more, that that one size treatment doesn't work for. Uh, it doesn't now, you know, we're ex - we're, but we're still growing. So I wanna see where those targeted treatment options come in -

James Hiter (21:28):

Yeah.

Montessa Lee (21:28):

For small cell.

James Hiter (21:29):

Yeah. It's exciting to think about the idea of, like, a, the equivalent of a biomarker test, uh, for small cell, and that that would lead to a very targeted treatment for the type of small cell that you have. Mm-hmm. And it's not that hard to imagine that we're. I mean, I was just talking to a researcher, uh, in the last couple of months who's working on this very thing. Yes. Trying to find those proteins that are similar - uh-huh. And, you know, where are the commonalities and how do we figure that out?

Montessa Lee (21:58):

Mm-hmm. Yep. And taking more of that research that's in the lab now. It is rapidly developing, and, and I, my hope, and I know it's gonna happen, is that now more of that research is gonna come to the clinic side. It's gonna expand to more patients, and that you just don't have to go to a research-based hospital to get this. It'll be at your local clinic. Yeah. You know, and so everyone will have these options, and I always stress that S - Yes. Because this is where we got to.

James Hiter (22:23):

What are the takeaways that you would have somebody, um, pull from this conversation? Mm-hmm.

Montessa Lee (22:28):

And James, you and I have known each other for a while, so even you can see the growth and I think p - um, anybody, patients, caregivers watching this now, I want to let everybody know you are in a different world now. Matter of fact, I've been binge watching that, so that's probably why that term came to my mind, a different world. But we are living in a different world for lung cancer. So years ago, we, we wouldn't have had this conversation, but if there's any time to be diagnosed, it's now, as there's rapid involvement in that we are on the cusp of new developments, in the cusp of, you know, get- getting treatment, that's. I can hear it even in the chats where people are talking about different treatment options they're experiencing, and other people can chime in. And so we are on that growth of getting more targeted or, or hopefully personalized treatment options for everyone.



James Hiter (23:15):

Yeah, that's so, uh, uh, so helpful. I, I, I think, you know, the one thing that I really hope people pull from this is also this, and we've talked about it a lot, you're not in it alone. You know, there are people who have been through it. Um, there are people who can talk to you, um, and you're not in it alone.

Montessa Lee (23:38):

That's a very good takeaway. Um, and I hear that a lot, like, in some of the social media groups I follow, because often that's their only question, "Has anybody experienced this?" Mm-hmm. I'm new to this group. My mom was just diagnosed with small cell lung cancer. Is anybody. Has anybody on here lived past a couple of months or a year? And I can say, "I have." And other people chime in, "I have, I have seven years, eight years, 10 years." And so it's amazing.

James Hiter (24:05):

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