

- Dr. Raymond Osa...: And I think we're now beginning to enter the point at which we can believe that at worst, lung cancer becomes a chronic illness that people don't have to die from.
- Diane Mulligan: Advances in lung cancer treatments over the last few years have made it possible to live with lung cancer for years after diagnosis. Today, a conversation with lung cancer patient advocates living with lung cancer, as they shared their stories at a recent workshop where they learn to amplify the impact of their voices. I'm Diane Mulligan.
- Sarah Beatty: And I'm Sarah Beatty. We'll also hear the inspiring and motivational message from a lung cancer specialist on what sets these patient advocates apart. Thanks for joining us today on the Living With Lung Cancer: Hope With Answers podcast.
- 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 finding new breakthrough treatments and others who are working to bring hope into the lung cancer experience.
- Diane Mulligan: Each spring, LCFA brings you together an amazing group of lung cancer patient advocates for a weekend of learning and conversation. Advocates get to hear research updates from some of LCFA's young investigators and details on the latest developments in lung cancer from world-renowned thoracic oncologists.
- Sarah Beatty: This year, the meaning looked a little different because of the virtual format, but LCFA co-founder Kim Norris brought the group together with a fascinating discussion about the power of the patient voice.
- Kim Norris: Patients may not realize just how powerful their voice can be in their own lung cancer treatment plan or in helping others through their journey. Patient voices are especially important and powerful, and research-focused nonprofits like LCFA and patient groups that focus on specific types of lung cancer.
- Sarah Beatty: And this year, we were so lucky to be joined by thoracic oncologist, Dr. Raymond Osarogiagbon of Baptist Cancer Center in Memphis, Tennessee. He set the stage for using the power of the patient voice to explain what it means to be living with lung cancer.
- Dr. Raymond Osa...: It is exciting though that where we are with lung cancer is a changing dialogue. We're going from embarrassment, frustration, maybe a little bit of negativity, to becoming more upbeat. And it is exactly people like you actually, who will help

us flip that story into a survival story. So others entering the arena for the first time don't get so overwhelmed by the darkness all around it that they fear to navigate through to the other end.

- Sarah Beatty: Kim, one of the most exciting things that Dr. O and by the way, he asked us to call him Dr. O. One of the most exciting things that he talked about is the hope for people who are diagnosed with lung cancer today.
- Kim Norris: Yes, it's a real change that's just happened over the last 5, 10, 15 years. When I first got into lung cancer patient advocacy years ago, the treatments available and the survival rates were not encouraging. Now, there's so many reasons for newly diagnosed patients to be hopeful.
- Dr. Raymond Osa...: We are making a lot of progress in lung cancer, and that is true. And that progress has come very quickly. It seems like literally every few weeks, every few months, there's a new groundbreaking discovery.
- Dr. Raymond Osa...: For many years, I have encouraged my patients just do the best you can to stay alive. The cycle of discovery is beginning to quicken. And the longer you are healthy, the longer you stay alive, the greater the odds that something comes in that rescues you from those problems. And I think we're now beginning to enter the point at which we can believe that that is not just pie in the sky, but that is something that we can expect to happen someday, where at worst, lung cancer becomes a chronic illness that people don't have to die from.
- Kim Norris: That outcome was almost unimaginable just a few years ago. It's the reason we started LCFA: to fund lung cancer research that changes the trajectory of the lives of people diagnosed with lung cancer.
- Diane Mulligan: We work with a group of people living with lung cancer to help spread awareness, information, and understanding of the importance of research funding. Dr. O talked about how important, how critical these patient groups are to changing the experience of so many others.
- Dr. Raymond Osa...: We are emerging from the dark ages, but we're closer to the dark than to the light still with lung cancer, as each one of you is actually a self-selected person. Self-selected for life in the sense that each one of you not only was diagnosed with lung cancer, but most of you know the driver of your lung cancer, and most of you have been able to attach to your lung cancer, the key that opens the door to longer survival, your targeted therapy. As for you, so it ought to be for everyone. But unfortunately, that is not how it is. So the claim, the challenge is, what is going on and what can we do about it?

Diane Mulligan: Are you 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. Just text LCFAmerica to 41444 to join in this important fight.

Sarah Beatty: For the past several years, we've been so fortunate to spend time with a number of lung cancer patient advocates at an annual get-together in California. This year, we listened virtually as the group talked about the power of finding your tribe, lung cancer patient advocates who share the same experience, and sometimes even the same biomarker.

Diane Mulligan: This shared experience often helps newly diagnosed patients find their own voice to advocate for the best treatment plan. As more people are living longer, healthier lives with lung cancer, many find meaning in advocating for others, helping newly diagnosed patients know the right test to get, and the right questions to ask to be part of their own treatment plans. Some turn their advocacy into activism, lobbying for increased lung cancer funding, and raising awareness of lung cancer as the number one cancer killer.

Kim Norris: Finding and connecting with other lung cancer patients is much easier today. Thanks, of course, to a quick Google search, but it helps to know what you're searching for. Searches like lung cancer survivor stories or KRAS patient groups will generally lead to useful and actionable information that can help patients connect to others going through the same experience, as advocate Terri Conneran learned.

Terri Conneran: When I found out I was diagnosed, all I wanted to keep thinking was I want to see somebody on the other side that looked like they got through it. Where do I find these people, and what do I do? The first thing my doctor said is stay off of Google because you're going to see nothing but bad news. I'd nowhere to turn. Then when I actually did connect with a local lung cancer group that kind of led from one thing to another, I walked in and saw the different groups, the EGFR, and the ALK.

Terri Conneran: I was like, I want to know what I am. They went back and that's when I went asking for my doctor, "What am I?". And she's like, "Well, you just have a PD-L1."

Terri Conneran: I didn't know that I had anything else. I kept pushing because I knew the language listening to everybody else. I went looking for it and didn't find it until I found out it was KRAS three years later. Then I had a group of people that I could connect with. Well, there should be a group of people cause it's the most common, but being there wasn't. I had to start it.

- Terri Conneran:** So now, the KRAS Kickers is bringing that group of people together so that we can connect. We have that sense of commonality around the same target therapies, the same frustrations, the same issues that sometimes it's just like regular life, right? Because you want to see light at the end of the tunnel, and you want to see somebody got through what it is that you're going through. So, I find more hope and more inspiration listening to the people in that particular biomarker group. Then, I do any other way.
- Diane Mulligan:** It's so important that lung cancer patients develop their voice to advocate for their own care. Patient groups can help them find the right questions to ask and the right test to have done.
- Kim Norris:** This is a much different experience today with so many lung cancer patients surviving and thriving for years after diagnosis. Imagine what it was like for Linnea Olson. When she was diagnosed in 2003, there were almost no lung cancer survivors at all.
- Linnea Olson:** For me, the first three years after my diagnosis, I didn't know anybody with lung cancer. As the years have gone on, I've met more and more people in different biomarker groups, but we all have this amazing thing. It's like a family and I'm going to get emotional here. But what I get from knowing other people is love. I mean, it's astounding. Whenever we do get together, physically get together, I mean, we have so much fun. You wouldn't think we have lung cancer and the love is palpable. I'm humble because lots of times it's people young enough to be my children, and I'm getting to the point where they could be my grandchildren, and we're all friends. It's phenomenal.
- Kim Norris:** 5, 10, even 15 years doesn't sound like a long time. But in lung cancer research, it's an eternity. More new treatments have been approved in the past five years than have been approved in the last 20 combined. And new discoveries are continually happening at such a rapid pace that is sometimes hard to keep up with them all.
- Diane Mulligan:** Thanks to lung cancer research, now there are people living with lung cancer for 5, 10, even 15 years after diagnosis. People going through the same experiences who can help those newly diagnosed lung cancer patients and help learn the right questions to ask. Some people, like Ivy Elkins, used a web search just to connect with others living with lung cancer.
- Ivy Elkins:** When I first was diagnosed and I found out very quickly that I was EGFR. But one thing that also helped me was I looked for... I actually did go on Google, even though I was told also not to. But I looked for blogs and other people, other women my age with kids who were putting their stories out there, there was stuff out there. It didn't necessarily matter at that point so much for me, what

biomarker they were, like you said Linnea, it was just the fact that they were people in the same stage of life as me, who were managing to live with lung cancer. That was incredibly helpful for me. But having those blogs out there with people's personal stories, that was huge.

Kim Norris: One challenge facing newly diagnosed patients is a steep learning curve of learning an entirely new vocabulary. As you have on Yovana Portillo found out.

Yovana Portillo: Once I was diagnosed, had my surgery, my family and friends were great. I thought I was going to be back at work in two weeks, and I had just had lung surgery. Then when it hit me mentally, because everything was happening so quick, all these new terms. Once it hit me mentally, it was two weeks after surgery. And yes, I did a Google search and I was like, 'lung cancer support group'. I need to find other people that have been through this before me so that I know I have to do it.

Yovana Portillo: I ended up finding a local lung cancer support group through the cancer support community here in Arizona, which they have monthly meetings. They've been a great part of my life, and that's where I started sharing my story. But yeah, it was important to find others that had been through the experience you were going through actively.

Kim Norris: One benefit of finding your tribe is finding the strength to ask questions of your doctor. Question treatments, ask about other options for your lung cancer, and even ask for a second opinion.

Diane Mulligan: A.J. Patel says many newly diagnosed lung cancer patients are hesitant to question their doctor or ask for that second opinion.

A.J. Patel: What if I discuss that with my doctor and he or she gets upset with that, or is not happy with that? I mean, we've got to move away from that thinking. We're not in the business of keeping people happy. We patients, we people. Because anyone could get cancer, let alone lung cancer. We need to advocate. We need to stand up and question, "Does this make sense?". Just because you're educated and put a white coat on and have that license, it doesn't make you right. It doesn't make you wrong either. So we have to be respectful. But if they don't bring their A game to the table, then we've got to point that out. You're not doing service to your clients, your service to your patients.

Diane Mulligan: Thanks to research, there are so many more people living longer with lung cancer. Many advocates find that by being involved in the patient advocate community, they can contribute to making the process easier on others.

Kim Norris: Small cell lung cancer patient advocate Montessa Lee was galvanized into action when she found information on how little had changed in small cell lung cancer treatments.

Montessa Lee: I went to Google doctor and turned my anger after seeing the result of both my grandfathers died of lung cancer and seeing that nothing really had changed. I turned that anger into advocacy.

Kim Norris: We heard how some advocates use their anger, frustration, and sadness as motivation for their advocacy.

Diane Mulligan: Yovana Portillo, Linnea Olson, and Gina Hollenbeck share what motivates them to continue their advocacy work.

Yovana Portillo: I think I use the memories of those people that I have lost from the lung cancer community to give me that drive that I need. Because I'm like, why am I doing this? I feel very fortunate that I am an early stage. Sometimes I feel I had survivor's guilt at the beginning, as I would see other members of my support group passing away. It was like, wow, I knew that I was lucky and I know that I'm lucky. So it's like, I need to share my voice. I need to share my story. I need to fight for those that we lost and how can I do that? How can I work towards that? How can I make a difference in the lung cancer community?

Linnea Olson: You know what else? You can also be angry. I think that sometimes that is what fuels me. I mean, I certainly believe in what I'm doing and it's my love for people that got me into advocacy in the first place. But it's my sense of injustice that sometimes really fuels me. What Yovana said about getting strength from others, I mean, when someone passes that I'm close to, or even not close to, and particularly when they're young, it makes me so angry. I think that's part of why I personally embrace sort of the war metaphor simply because I do consider this like a battle in where I kind of cleanse myself of what some people don't like about the war metaphors. I don't see anyone losing a battle, but I do feel that I fight on in the memory of, and for those who have passed.

Gina Hollenbeck: Not sure if everybody feels like this, but one of the things that Linnea said recently was it just feels like a gut punch when we lose it. You physically feel that, and I'm sure all of you have felt that. It feels like, to me, you're just hunkered down like that gut punch in your stomach and it makes you almost physically sick. When I experienced that, then my next thing is I'm coming back with an uppercut that says, "I'm going to use my voice, and I'm going to tell you as loud as I can, that biomarkers matter. We need better clinical trials."

Gina Hollenbeck: We need to make sure that patients from where you live should not determine if you live. I just think that it's so important that we just keep on coming back

with that uppercut. So, any energy that I can give to you guys, I hope that I can, but I get so much energy from each one of you. When I hear all of the amazing things that you're doing, so that's my uppercut to say, "Come on, I'm fighting back."

- Diane Mulligan: I love that enthusiasm in Gina's voice. She's a fighter who's helping others through her own lung cancer journey.
- Kim Norris: You all listen to Frank McKenna as he summed up the conversation with his take on what he gets out of helping other people.
- Frank McKenna: I think it's important that we stay involved in things like this. Even if we don't personally reach out and need that help, I think so many people rely on our experiences and they reach out to us. It's just, I think it's been very rewarding to me when somebody says you've been a godsend because you've given me this information, I can't get it anywhere else. That's just, I mean, I guess that's our purpose here, as we're trying to spread the word and be the advocates for this, but it does work. I know a lot of other people are involved in some of the same groups I am in and probably experienced that same thing.
- Diane Mulligan: We are so grateful to all the members of the LCFA Speakers Bureau, patient advocates who embody what it means to be living with lung cancer.
- Sarah Beatty: Thank you to LCFA co-founder Kim Norris for joining the conversation on Hope With Answers: Living With Lung Cancer podcast. Join us next time.
- Diane Mulligan: Make sure to subscribe to the Hope With Answers: Living With Lung Cancer podcast. You'll be notified every time a new episode is available. So visit us online at lcfamerica.org where you can find 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.