



Episode Show Notes

Episode Title:

Understanding ROS1 Positive Lung Cancer: Expert Insights with Dr. Alice Shaw

Publish Date: November 30, 2025

Episode Description

ROS1-positive lung cancer is rare—affecting only 1-2% of patients—but highly treatable with targeted therapies. In this episode, host Annabelle Gurwitch sits down with Dr. Alice Shaw, Director of the Center for Thoracic Cancers at Dana-Farber Cancer Institute, for an in-depth conversation about this oncogene-driven lung cancer.

Dr. Shaw explains why having an identifiable genetic target is actually good news, how next-generation ROS1 inhibitors are transforming outcomes with better brain penetration and fewer side effects, and why comprehensive biomarker testing is essential for every non-small cell lung cancer patient.

Learn about the rapid evolution of ROS1 treatments, how to access clinical trials while maintaining your local care team, and why specialized care matters for rare mutations. Whether you're newly diagnosed, a caregiver, or seeking to understand the latest treatment advances, this conversation provides hope through scientific progress—not empty platitudes, but real breakthroughs that save lives.

Guests

Annabelle Gurwitch – Host, Author, and Patient Advocate

New York Times bestselling author and LCFA Speakers Bureau member living with stage IV EGFR+ lung cancer. Annabelle brings compassion, wit, and unflinching honesty to conversations



about the real challenges of living with lung cancer. Diagnosed five years ago, she uses her platform to advocate for patients and raise awareness about treatment advances.

Connect: <https://www.annabellegurwitch.com/> | @annabellegurwitch

LCFA Profile: <https://lcfamerica.org/speaker-profile/annabelle-gurwitch/>

Dr. Alice Shaw – Director, Center for Thoracic Cancers, Dana-Farber Cancer Institute

Dr. Alice Shaw is an internationally recognized expert in targeted therapies for lung cancer, particularly for patients with ALK and ROS1 rearrangements. As Professor of Medicine at Harvard Medical School, her groundbreaking research has been instrumental in developing and testing next-generation targeted therapies that have transformed outcomes for patients with rare oncogene-driven lung cancers. Dr. Shaw's work focuses on precision medicine approaches, including developing drugs that penetrate the blood-brain barrier to treat and prevent brain metastases.

Connect: <https://www.dana-farber.org/thoracic-oncology/>

Key Topics

- What "oncogene-driven" lung cancer means and why it's good news
 - The critical importance of comprehensive biomarker testing
 - Tissue vs. liquid biopsy: when to use each test
 - Understanding ROS1 rearrangements and their rarity (1-2% of patients)
 - Evolution of ROS1 targeted therapies over 15 years
 - Next-generation ROS1 inhibitors: increased potency and selectivity
 - Brain penetration: treating and preventing brain metastases
 - Clinical trial participation and timeline to FDA approval
 - How to access trials while maintaining your local care team
 - Why specialized care matters for rare mutations
 - Patient advocacy and second opinions
 - Hope through scientific advancement
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Key Takeaways



- **Get Comprehensive Testing** – Both tissue and liquid biopsy should be performed for all NSCLC patients; molecular testing directly impacts treatment selection
 - **Oncogene-Driven Is Good News** – Having an identifiable genetic target means effective targeted therapies exist
 - **ROS1 Patients Are "Rare and Exceptional"** – Only 1-2% of lung cancer patients have ROS1 rearrangements, but highly effective treatments are available
 - **Next-Generation Drugs Are Game-Changers** – Newer ROS1 inhibitors are more potent, selective, and penetrate the brain to treat and prevent metastases
 - **Clinical Trials Offer Cutting-Edge Access** – The newest, most effective treatments are often available first through trials; timeline from first testing to FDA approval can be just 3.5-4 years
 - **You Can Keep Your Local Team** – Patients can participate in trials at specialized centers while maintaining care with their local oncologist
 - **Specialized Care Matters** – Because ROS1 is so rare, seek consultation with thoracic oncologists experienced in targeted therapies
 - **Advocate for Yourself** – Ask questions, seek second opinions, and stay informed about treatment advances
 - **Hope Is Scientific Progress** – Real advancements in research translate to longer, better lives for patients
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Powerful Quotes

"If you're told you have an oncogene-driven lung cancer, that's generally good news. It means your oncologist has identified a specific genetic alteration driving your cancer's growth, and targeted therapies exist that can specifically turn off that abnormal gene." – Dr. Alice Shaw

"I always tell my patients who have ROS1 that they're rare and exceptional." – Dr. Alice Shaw

"These new ROS1 drugs penetrate into the brain and actually not only treat brain metastases if they're there, but also potentially prevent brain metastases from forming. That is huge." – Dr. Alice Shaw

"Many of my patients stay with their local team while participating in trials. You don't necessarily have to say, 'I'm going to lose my whole team that I've been working with.'" – Dr. Alice Shaw

"The pace of drug development is so rapid. There's just no way you can access the newest drugs that are likely to be even more effective with fewer side effects unless you actually know about the clinical trials." – Dr. Alice Shaw



"When I think of the word hope, I think about advancements in science. Hope is actually looking and seeing at the advances. And even since I was diagnosed five years ago, the advances are amazing." — Annabelle Gurwitch

"Life has an expiration date. Acknowledging that is actually empowering—it makes you want to live more fully." — Annabelle Gurwitch

Resources Mentioned

LCFA Resources

- **LCFA Website:** <https://lcfamerica.org>
- **Living With Lung Cancer AMA Podcast:** <https://lcfamerica.org/living-with-lung-cancer/ask-me-anything/>
- **LCFA Speakers Bureau:** <https://lcfamerica.org/speakers-bureau/>
- **LCFA Clinical Trials Database:** <https://lcfamerica.org/resources/find-clinical-trial/>
- **LCFA Second Opinion Resources:** <https://lcfamerica.org/resources/second-opinion/>

Patient Advocacy & Support

- **Elevate Lung Cancer Care** - Learn about your advanced ROS1+ or ALK+ non-small cell lung cancer (NSCLC) diagnosis and ways to navigate care plan discussions - <https://elevatelungcancercare.com/>
- **ROS1ders** – Patient community specifically for ROS1-positive lung cancer patients, <https://www.theros1ders.org/>
- **ClinicalTrials.gov:** <https://clinicaltrials.gov/>
- **LCFA Resources:** Online patient communities and support groups - <https://lcfamerica.org/resources/?topic%5B0%5D=community&topic%5B1%5D=online-community&topic%5B2%5D=patient-support>

Financial Assistance

- **Pharmaceutical patient assistance programs listed in LCFA Resources:** <https://lcfamerica.org/resources/?topic%5B0%5D=financial-assistance>
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Action Steps



For Patients & Caregivers:

- **Ask your oncologist these three questions:**
 - What kind of lung cancer do I have?
 - Have molecular or genetic tests been done?
 - Does my lung cancer have any targets?
- Request both tissue and liquid biopsy testing
- Keep copies of all test results and pathology reports
- Seek consultation with thoracic oncologists experienced in ROS1
- Ask about clinical trials, and don't hesitate to seek care at specialized centers
- Join ROS1ders or other ROS1 patient communities
- Advocate for yourself: seek second opinions when needed
- Stay informed about treatment advances and new drug approvals
- Explore financial assistance programs for testing and treatment

For Healthcare Professionals:

- Ensure comprehensive molecular testing for all NSCLC patients
- Perform both tissue and liquid biopsy when possible
- Discuss clinical trial options proactively
- Connect patients with specialized thoracic oncology centers
- Facilitate collaboration between local and specialized care teams
- Provide information about patient advocacy groups like ROS1ders
- Stay current on next-generation targeted therapy developments
- Educate patients about the benefits of having an oncogene-driven cancer

About the Podcast

Living With Lung Cancer: Ask Me Anything is LCFA's survivor-led podcast that strips away clinical jargon to reveal what living with lung cancer really looks like. Hosted by New York Times bestselling author Annabelle Gurwitch and endurance runner James Hiter, this podcast hands the microphone to those who know this disease best—lung cancer survivors and the experts who treat them.

No topic is off-limits. No question is too uncomfortable. No experience is too raw to share. Each episode features candid conversations about navigating healthcare, advocating for yourself, and finding hope through scientific advancement.

Raw conversations. Real survivors. No filters.



About LCFA

Lung Cancer Foundation of America improves lung cancer survivorship through funding transformative science, raising public awareness, and providing access to information, hope, and contemporary treatment options. Since 2007, LCFA has invested \$4.4 million in lung cancer research, generating \$43 million in follow-on funding.

Learn more: <https://lcfamerica.org> | **Donate:** <https://lcfamerica.org/donate>

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Topics: ROS1, Targeted Therapy, Biomarker Testing, Clinical Trials, Lung Cancer Research, Oncogene-Driven Cancer, Brain Metastases, Precision Medicine, Patient Advocacy

SEO Focus: ROS1 Positive Lung Cancer, ROS1 Inhibitors, Targeted Therapy for Lung Cancer, Biomarker Testing, Clinical Trials, Next-Generation Cancer Treatment

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