



Living Long-Term with Lung Cancer: Clinical Trials, ROS1, and 14 Years of Hope Show Notes

Brief Episode Summary

Patient advocate Lysa Buonanno joins host Annabelle Gurwitch for an honest, hope-filled conversation about what it really means to live long-term with stage 4 lung cancer. Diagnosed at age 40 with ROS1-positive lung cancer—before biomarker testing was standard of care—Lysa is now 14 and a half years into her journey and a brand-new grandmother. Together, they pull back the curtain on multiple lines of treatment, the realities of clinical trial participation, the life-saving power of patient community, and why self-advocacy can change everything. This episode is for anyone newly diagnosed, considering a clinical trial, or seeking proof that long-term survival with lung cancer is possible.

What We Cover in This Episode

The Power of Connection: Why finding a community that "walks in your shoes" provides a level of support that even the most loving family can't match.

Radical Self-Advocacy: How Lysa bypassed standard care to discover biomarker testing and underwent surgery specifically to secure tissue for sequencing.

The Clinical Trial Reality Check: A candid look at the "logistical burden" of trials, from self-enrolling to the frustrations of delayed travel reimbursements and rigid meal allowances.

Changing the Lexicon: Why we must stop saying "the patient failed the drug" and start saying "the drug failed the patient" to remove guilt and empower shared decision-making.

Living for the Silver Linings: Navigating identity and career changes over 14 years, culminating in the milestone Lysa once thought impossible: becoming a grandmother.

Guests

Annabelle Gurwitch – Host, Author, and Patient Advocate

New York Times bestselling author and LCFA Speakers Bureau member living with stage 4 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.



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

Lysa Buonanno - Patient Advocate | ROS1+ Survivor & Mentor

Lysa was diagnosed with stage 4 ROS1-positive lung cancer in 2011 at age 40, long before biomarker testing was standard of care. After learning about precision medicine through an online patient group, she fought for better care, switched oncologists, and underwent surgery solely to access biomarker testing. Now 14 and a half years into her journey and on her fifth line of treatment via a Phase 1 clinical trial, Lysa is a passionate mentor to newly diagnosed patients, an advocate for lung cancer research funding, and a brand-new grandmother. She lives by the belief that knowledge – and community – are power.

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 Second Opinion Resources: <https://lcfamerica.org/resources/second-opinion/>
- Biomarker Testing Information: <https://lcfamerica.org/lung-cancer-info/diagnosing-lung-cancer/biomarker-testing/>
- Treatment Options Overview: <https://lcfamerica.org/lung-cancer-info/treatment/>

Find Specialized Care

- **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/>

Patient Advocacy & Support Communities

- EGFR Resisters – Patient community for EGFR+ lung cancer: <https://www.egfrresistors.org/>
- ALK Positives – Patient community for ALK+ lung cancer: <https://www.alkpositive.org/>
- ROS1ders – Patient community for ROS1+ lung cancer: <https://www.theros1ders.org/>

Medical Disclaimer

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