



**Stronger Together:**  
*EGFR Resisters' Patient  
and Caregiver Summit*

# Living with *EGFR*-mutated Lung Cancer

EGFR Patient & Caregiver Summit – Session 3

# Recording Notice

Please be advised that this session and all general sessions of the *EGFR Resisters' Patient & Caregiver Summit* are being livestreamed and recorded.

Recordings will be made available on the EGFR Resisters website and accessible to the public.

**By participating in this event, you consent to the recording and distribution of these sessions.**

If you have any concerns, please speak with event staff.

# Session Objectives

- Recognize the all-encompassing gravity of living with EGFRm lung cancer, including the physical, emotional, psychosocial, financial, and logistical burden borne by patients and caregivers.
- Describe key facets of "whole-person" care in the management of EGFRm lung cancer, highlighting best practices for mitigating burden, achieving comprehensive patient-centricity, and supporting overall well-being.
- Review resources from the EGFR Resisters and the vital role of community in optimizing quality of life.

# Session Speakers

**Victoria Sherry, DNP, CRNP, ANP-BC, AOCNP**

Adult Oncology NP for Thoracic Malignancies  
Advanced Senior Lecturer  
University of Pennsylvania  
Philadelphia, PA

**Susan C. Scott, MD**

Assistant Professor of Oncology  
Thoracic Oncologist  
Johns Hopkins University School of Medicine  
Baltimore, MD

**Stephanie Alonso, MSW, LCSW, OSW-C**

Outpatient Oncology Social Worker  
University of Chicago  
Chicago, IL

**Daniel West**

Patient Advocate  
Houston, TX

# Social Worker Perspectives

# Living with *EGFR*-mutated Lung Cancer – *Social Worker Perspectives*

## *Recognizing the Impact on the Whole Person*

- Cancer affects the whole person in a multi-faceted manner
  - Work, school, family and social roles, self-understanding, goals, and life meaning
- Cancer creates and exacerbates psychological and psychosocial challenges
  - New or worsening mental health comorbidities (i.e., anxiety, depression, social isolation)
- There is common ground and solidarity in the patient experience with cancer, but every individual care journey is unique
  - Type of treatment (i.e., oral vs. infusion, targeted therapy vs. chemotherapy, etc.)
  - Age/life stage/disease stage (i.e., young parents vs. retired seniors)
  - Nature of work/occupation (in-office vs. remote, desk job vs. physically demanding labor)
- New obligations and added responsibilities
  - Financial burden, time away from work, frequent medical appointments

# Living with *EGFR*-mutated Lung Cancer – *Social Worker Perspectives*

*Caring for the Whole Person*

- The interprofessional and multidisciplinary clinical cancer care team is essential for managing *EGFRm* lung cancer
  - i.e., oncologist, surgeon, pulmonologist, PCP, APRN/nurse, PA, pharmacist
- However, whole-person care integrates a host of other team members
  - Social worker
    - Help meet practical needs (i.e., transportation, lodging, power of attorney, basic insurance and financial hurdles, etc.) and “direct traffic” to other team members and resources
  - Psychiatrist, psychologist, licensed counselor/therapist, support group
  - Insurance specialist, patient navigator
  - Integrative medicine specialist (i.e., palliative care, dietetics, massage, acupuncture, etc.)
  - Patient advisory board, peer support (i.e., self-advocacy)

# Living with *EGFR*-mutated Lung Cancer – *Social Worker Perspectives*

## *Community & Support Outside the Hospital*

- Addressing the holistic needs of patients living with lung cancer requires a comprehensive and collaborative effort that extends far beyond the hospital walls
- Education and Community
  - EGFR Resisters, LUNGeivity, GO2 for Lung Cancer, CancerCare, American Cancer Society
- Practical Resources
  - Triage Cancer, Cancer and Careers
- Emotional Support Networks
  - Gilda's Club, Imerman Angels, Wellness House, Cancer Support Community

# Patient Perspectives



# Living with *EGFR*-mutated Lung Cancer – *Patient Advocate Perspectives*

*The True Gravity of Living with Cancer*

- It's not just about the cancer – *it's about everything it touches*
- The immense weight of the unknown
- Daily burdens (i.e., pain, treatment-related toxicities, quality-of-life detriments)
- Impacts far beyond the physical
- The unique load carried by caregivers (and other loved ones)
- 'Kernels of hope' for those living with *EGFRm* lung cancer

# Living with *EGFR*-mutated Lung Cancer – *Patient Advocate Perspectives*

*Treating More than the Tumor*

- My most healing moments – *when my care team saw me and my family, not just my medical chart*
- Whole person care = simultaneous management of physical, mental, and emotional well-being, on an individual patient basis
  - Note – comprehensive care must also include a focus on *dignity, empathy, and equitable access to information*
- What helped me the most:
  - A multidisciplinary, integrated care team
  - Clear communication and shared decision-making (i.e., I want to be part of the plan and have a say)
  - Practical support (i.e., managing side effects, navigating insurance logistics)
  - Space to talk about hope and fear, not just treatment options and data

# Living with *EGFR*-mutated Lung Cancer – *Patient Advocate Perspectives*

*The Power of Community*

- *Finding community changed things for me*

- LUNGeivity, Patient and Family Advisors (PFAP) at MD Anderson, EGFR Resisters
- *Community turns isolation into empowerment*
- *Community = hope, advocacy, and progress*

- We live with this disease, *but we are not defined by it*

- What community provided me:

- Education on treatments and trials
- Shared experiences that normalized my fears
- Emotional support that even the best doctors cannot provide

- *“When we come together, we change what’s possible for every patient who comes after us.”*

# Living with *EGFR*-mutated Lung Cancer – *Patient Advocate Perspectives*

*The Power of Community*

***“Medicine extends our lives, but it is the people around us that give life meaning.”***

# Physician Perspectives

# Effects of Cancer Treatment – *Physician Perspectives*

*Pearls from a Thoracic Medical Oncologist*

- Counseling patients about potential risks and benefits
- Shared decision-making
- Active and proactive symptom management

**What about the provision of patient-friendly resources?**

# Assessing Availability and Demand for Patient-Friendly Resources in Lung Cancer Care: *The Patient Perspective*

**Eric K. Singhi<sup>1</sup>, A. Desai<sup>2</sup>, F. Abu Rous<sup>3</sup>, J. Feldman<sup>4</sup>**

**<sup>1</sup>University of Texas MD Anderson Cancer Center, Houston/TX/USA ,<sup>2</sup>University of Alabama, Birmingham/AL/USA ,<sup>3</sup>Henry Ford Health System, Detroit/MI/USA ,<sup>4</sup>EGFR Resisters, Chicago/IL/USA**

Singhi E, et al. Presented at IASLC WCLC 2023.

## Results

- At time of diagnosis, **95%** of patients and **67%** of caregivers/family members sought information about disease and treatments online

- **41%** of patients reported that the information they encountered online was **very difficult or difficult** to understand
- **40%** of patients were **neutral**

### **DIAGNOSIS**

- **76%** of patients reported that their oncology provider **DID NOT** provide patient-friendly resources with information about their disease
  - **93%** of these patients would have preferred to receive such resources from their provider

### **TREATMENT PLAN**

- **55%** of patients reported that their oncology provider **DID NOT** explain the data behind their treatment plan
  - **85%** of these patients would have preferred to have such information presented in a way they could understand

Singhi E, et al. Presented at IASLC WCLC 2023; Brazel D, et al. *Adv Cancer Ed Qual Improvement*. 2025.

# Effects of Cancer Treatment – *Physician Perspectives*

*Pearls from a Thoracic Medical Oncologist*

- Counseling patients about potential risks and benefits
- Shared decision-making
- Active and proactive symptom management

**How important is treatment-related toxicity management for patient-reported outcomes (PROs), including quality-of-life?**

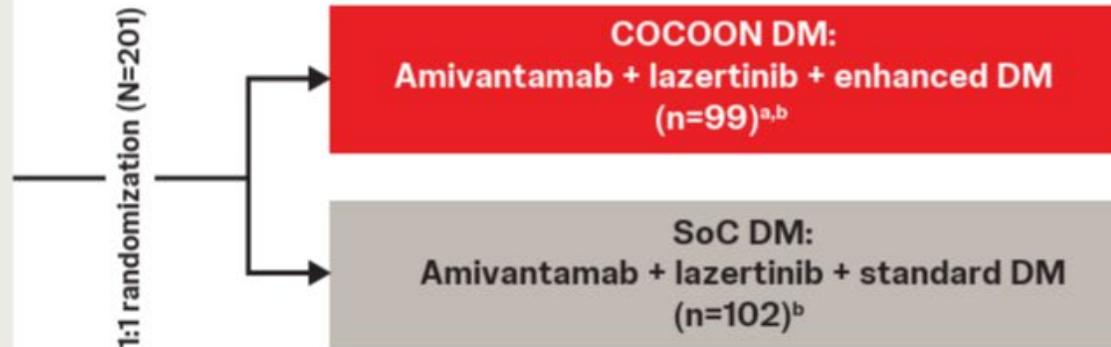
# FIGURE 2: Phase 2 COCOON study design

## Key eligibility criteria:

- Locally advanced or metastatic NSCLC
- Treatment naïve for advanced disease
- Documented *EGFR* Ex19del or L858R
- ECOG PS score of 0 or 1

## Stratification factors:

- Race (Asian vs non-Asian)
- Age (<65 vs ≥65 years)



## COCOON regimen:

- Oral doxycycline or minocycline for 12 wk
  - Followed by topical clindamycin lotion on the scalp daily, starting at Week 13, for 9 mo
- Chlorhexidine on the nails daily for 12 mo
- Ceramide-based moisturizer on the body and face at least daily for 12 mo<sup>c</sup>

*SoC DM included general skin prophylaxis per local practice and reactive treatment, such as topical corticosteroids and systemic antibiotics*

**VTE prophylaxis was mandatory for the first 4 mo**

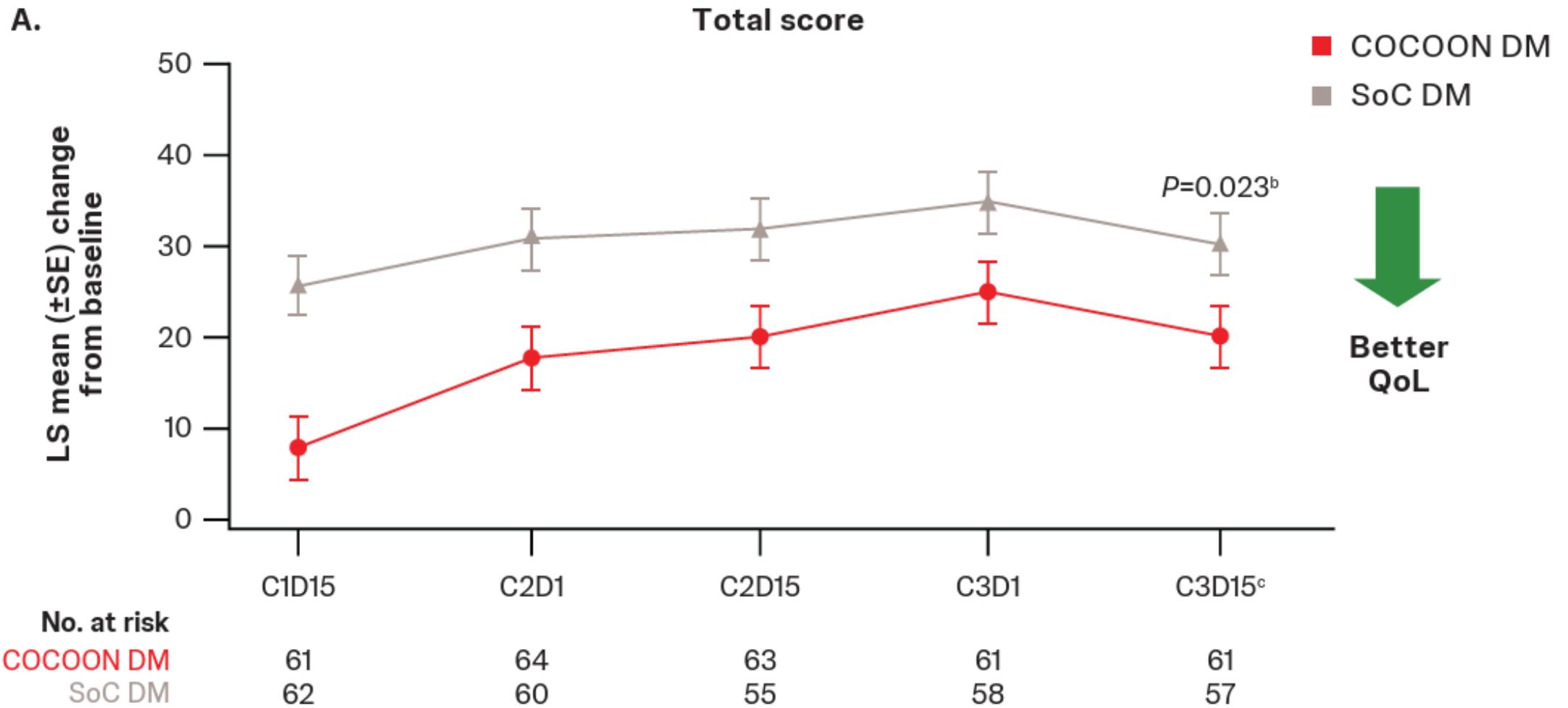
## Primary endpoint:

Incidence of grade ≥2 dermatologic AEs<sup>d</sup> in the first 12 wk after initiation of amivantamab + lazertinib treatment

## Select secondary endpoints:

PROs by Skindex-16 and PGI-S through 12 wk of follow-up<sup>e-g</sup>

Interim analysis planned for when ~70% of participants completed Week 12 assessments



DM, dermatologic management

Cho B, et al. *J Thoracic Onc.* 2025; Feldman J, et al. Poster Presented at ASCO 2025.

## Conclusions



At this analysis, which evaluated the first 12 weeks of treatment, participants in the COCOON DM arm experienced lower severity of dermatologic symptoms and a reduced impact on QoL than participants in the SoC DM arm



Substantial and consistent separation favoring COCOON DM was observed in all postbaseline Skindex-16 subscales



Most participants in the COCOON DM arm reported mild or no dermatologic symptoms

- This benefit was consistently observed across the first ~10 weeks of treatment



**Stronger Together:**  
*EGFR Resisters' Patient  
and Caregiver Summit*

# Q & A

EGFR Patient & Caregiver Summit – Session 3