# TODAY’S AGENDA

<table>
<thead>
<tr>
<th>Time</th>
<th>Presentation</th>
<th>Presenter(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>9:00-9:10</td>
<td>Welcome, roll call, housekeeping</td>
<td>Thomas Asfeldt, RN, MAN, MBA</td>
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<tr>
<td>9:10-9:45</td>
<td>Didactic Presentation: ECHO Session 12</td>
<td>Emily Tonorezos, M.D.</td>
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<td></td>
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<td>Jamie Studts, Ph.D.</td>
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<td>9:45-10:00</td>
<td>Q &amp; A/Discussion</td>
<td>Thomas Asfeldt</td>
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<tr>
<td>10:00-10:15</td>
<td>Program/Case Presentation:</td>
<td>Chizelle Archie, Grady Memorial</td>
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<td>10:15-10:25</td>
<td>Q &amp; A/Discussion</td>
<td>Thomas Asfeldt</td>
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<tr>
<td>10:25-10:30</td>
<td>Conclusion/Next session</td>
<td>Thomas Asfeldt, Dawn Wiatrek Octavia Vogel</td>
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*Sessions will be recorded.
*Please mute phones when not speaking. Mute cell phones and try to reduce extraneous noise.
*Remember to e-mail Octavia Vogel by 5/3 if you are requesting CME/CEU credit.
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■ The following planners and faculty disclose that they have no financial relationships with any commercial interest: (next slide)
FACILITATOR & PRESENTERS

Presenters:  
Jamie Studts, Ph.D.  
Professor, Department of Behavioral Science  
University of Kentucky College of Medicine  
Director, Behavioral and Community-Based Research Shared Resource  
University of Kentucky Markey Cancer Center

Emily Tonorezos, M.D.  
Internist, Adult Long-Term Follow up Program  
Memorial Sloan Kettering Cancer Center

Patient Case:  
Chizelle Archie  
GCCE Survivorship Coordinator  
Grady Memorial Hospital

Facilitator:  
Thomas Asfeldt, RN, MAN, MBA  
Director, Sanford Medical Center, Outpatient Cancer Services & Radiation Oncology  
Sanford Health
LEARNING OBJECTIVES

This session will provide an overview key topics in the transition to post-treatment survivorship including survivorship care plans/treatment summaries, transitions to primary care, and long term survivorship support.
What is survivorship?

- Monitor for recurrence.
- Manage toxicities.
- Prevent subsequent malignant neoplasm.
- Coordinate care between oncology and primary care providers.
### Lung cancer diagnosis is common

<table>
<thead>
<tr>
<th>Site</th>
<th>Males 870,970</th>
<th>Females 891,480</th>
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<tbody>
<tr>
<td>Prostate</td>
<td>20%</td>
<td>30%</td>
</tr>
<tr>
<td>Lung &amp; bronchus</td>
<td>13%</td>
<td>13%</td>
</tr>
<tr>
<td>Colon &amp; rectum</td>
<td>9%</td>
<td>7%</td>
</tr>
<tr>
<td>Urinary bladder</td>
<td>7%</td>
<td>7%</td>
</tr>
<tr>
<td>Melanoma of skin</td>
<td>7%</td>
<td>5%</td>
</tr>
<tr>
<td>Kidney &amp; renal pelvis</td>
<td>5%</td>
<td>4%</td>
</tr>
<tr>
<td>Non-Hodgkin lymphoma</td>
<td>5%</td>
<td>4%</td>
</tr>
<tr>
<td>Oral cavity &amp; pharynx</td>
<td>4%</td>
<td>3%</td>
</tr>
<tr>
<td>Leukemia</td>
<td>4%</td>
<td>3%</td>
</tr>
<tr>
<td>Pancreas</td>
<td>3%</td>
<td>3%</td>
</tr>
<tr>
<td>All other sites</td>
<td>22%</td>
<td>21%</td>
</tr>
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New cases of cancer in 2019, by site, in US adults (cancer.org)
Decline in lung cancer mortality

Trends in age-adjusted cancer death rates among US Males (cancer.org)
Decline in lung cancer mortality

Trends in age-adjusted cancer death rates among US Males (cancer.org)
Decline in lung cancer mortality

Estimated Number of Cancer Survivors in the U.S., by Site

Office of Cancer Survivorship
Decline in lung cancer mortality

Lung cancer survivorship

- Current population in US: 400,000
- Monitor for recurrence
- Manage toxicities
- Detect second malignancies
- Coordinate care
Monitor for recurrence

- Incidence of all lung cancers in the US is showing a downward trend.
- However, the proportion of stage I non-small cell lung cancer is increasing.
- From 1998 to 2007, the incidence rate of stage I lung cancer increased by 40%
Monitor for recurrence

- 1294 patients with early-stage NSCLC s/p resection underwent usual surveillance scans
- Median follow-up 35 months
- Recurrence: 257 (20%)
- Second primary lung cancer: 91 (7%)
- During the first 4 years after surgery, the risk of recurrence ranged from 6% to 10% per person-year but decreased thereafter to 2%.
- Risk of second primary lung cancer ranged from 3% to 6% per person-year and did not diminish over time.

Lung Cancer Survivorship

• Early-stage lung cancer survivors who are discharged to community providers:
  – Annual low-dose CT scan
Manage Toxicities

- Depression, anxiety, and poor health-related quality of life
- Fatigue
- Dyspnea
- Post-thoracotomy pain syndrome
Manage Toxicities

- Chemotherapy-related:
  - Neuropathy
  - Hearing loss
  - Neurocognitive changes
- Immunotherapy:
  - Dermatologic and gastrointestinal side effects
- Radiation:
  - Pneumonitis, esophagitis, cardiovascular disease, and skin changes

Manage Toxicities

- 183 NSCLC survivors 1–6 years post-surgical treatment completed questionnaires: pain, fatigue, dyspnea, depression, anxiety, HRQOL, and performance status
- Most survivors (79.8 %) had some degree of symptom burden, with 30.6 % reporting one clinically significant symptom, 27.9 % reporting two symptoms, and 21.3 % reporting three or more symptoms.
- Physical HRQOL significantly decreased as the degree of symptom burden increased.
- Two or more clinically significant symptoms are identified as the “tipping point” for showing adverse effects on HRQOL and functioning.

Manage Toxicities: Strategies

- Targeted rehab
- Acupuncture
- Comprehensive palliative care

Manage Toxicities: Strategies

Manage Toxicities: Strategies

- Exercise:
  - Improved symptom control
  - Better quality of life
  - Less anxiety and depression
Manage Toxicities: Strategy

- 116 patients from a medical centre in northern Taiwan, randomly assigned to either a walking-exercise group (n=58) or a usual-care group (n=58).
- Home-based, moderate-intensity walking for 40 min per day, 3 days per week, and weekly exercise counseling.

Manage Toxicities: Strategy

• The exercise group patients exhibited significant improvements in their anxiety levels over time ($P=0.009$ and $0.006$ in the third and sixth months, respectively) and depression ($P=0.00006$ and $0.004$ in the third and sixth months, respectively) than did the usual-care group patients.

Lung Cancer Survivorship

- Early-stage lung cancer survivors who are discharged to community providers:
  - Annual low-dose CT scan
  - Exercise program
    - 40 minutes fast walking 3 times a week
Manage Toxicities: Weight

- Underweight at time of diagnosis is associated with poorer outcomes in lung cancer survivors.
- Patients who do not gain weight during treatment have poor overall survival

Manage Toxicities: Weight

Lung Cancer Survivorship

- Early-stage lung cancer survivors who are discharged to community providers:
  - Annual low-dose CT scan
  - Exercise program
    - 40 minutes fast walking 3 times a week
  - Maintain a healthy weight
Surveillance for Subsequent Neoplasm

- Exposure based:
  - Second primary lung cancer
  - Tumors of the head and neck
  - Bladder cancer
- Treatment based
- Age-based
Surveillance for Subsequent Neoplasm

[Graph showing the cumulative incidence of SPLC over time, comparing nonsmokers and smokers.]
Tobacco cessation

- Persistent smoking in NSCLC survivors:
  - Treatment complications
  - Treatment-related toxicities
  - Poorer quality of life
  - Decreased adherence to therapy

Tobacco cessation

- 5 A's (ask, advise, assess, assist, arrange)
- AAR:
  - Ask about tobacco
  - Assist (advice, plan, medication)
  - Refer (behavioral resources)
- 3-1-1
- 1-800-QUITNOW
Lung Cancer Survivorship

• Early-stage lung cancer survivors who are discharged to community providers:
  – Annual low-dose CT scan
  – Exercise program
    • 40 minutes fast walking 3 times a week
  – Maintain a healthy weight
  – Tobacco cessation
Comorbid Conditions

- Atherosclerotic heart disease
- Peripheral vascular disease
- Emphysema
- Chronic Bronchitis
- Type 2 Diabetes
- Hypertension
Coordination of Care

- Surgical oncologist
- Medical oncologist
- Radiation oncologist
- Primary care provider
- Other medical subspecialty providers
Lung Cancer Survivorship

• Early-stage lung cancer survivors who are discharged to community providers:
  – Annual low-dose CT scan
  – Exercise program
    • 40 minutes fast walking 3 times a week
  – Maintain a healthy weight
  – Tobacco cessation
  – Manage comorbidities
Survivorship Care Plan (ACS)

- Suggested schedule for follow-up exams and tests
- Other tests you might need in the future, such as early detection (screening) tests for other types of cancer, or tests to look for long-term health effects from your cancer or its treatment
- List of potential late or long-term side effects from your treatment, including what to watch for and when you should contact your doctor
- Suggestions for things you can do that might improve your health, including possibly lowering your chances of the cancer coming back
Survivorship Care Plan (JF)

TREATMENT PLAN
Cancer treatment can be complicated and daunting. Patients need to understand what to expect from the point of diagnosis. A Treatment Plan lays out the goals and schedule for medical care. ¹

LEARN MORE ABOUT TREATMENT PLANS

Cancer Care Plan Builder 6.0
FOR HEALTH CARE PROFESSIONALS
Get help making personal Treatment Plans, Treatment Summaries and Survivorship Care Plans for your patients.

GET STARTED

Patient Tools for Cancer Care
FOR PATIENTS
Start a conversation with your doctor about your treatment and follow-up care. Get help managing the effects of treatment.
Lung Cancer Survivorship

• Early-stage lung cancer survivors who are discharged to community providers:
  – Annual low-dose CT scan
  – Exercise program
    • 40 minutes fast walking 3 times a week
  – Maintain a healthy weight
  – Tobacco cessation
  – Manage comorbidities
Thank you!
The Kentucky LEADS Collaborative Lung Cancer Survivorship Care Program

Jamie L. Studts, PhD

Professor
Department of Behavioral Science
University of Kentucky College of Medicine

Assistant Director
Cancer Prevention and Control
Lucille P. Markey Cancer Center
Lung cancer survivors commonly face a broad range of substantial challenges.

- Distressed
  - Remote – Lacking Access
  - Disengaged
  - Compromising Health Behaviors
- Intrusive Physical Symptoms
- Socially Isolated
Internalized Lung Cancer Stigma

Many individuals diagnosed with lung cancer harbor substantial internalized stigma and self-blame...

1) they may not be as engaged with treatment decisions,
2) they may not communicate symptoms or side-effects to clinicians,
3) they may experience higher levels of distress,
4) they may not engage social supports,
5) they may not adhere to treatment recommendations, and
6) they may experience poorer health outcomes (broadly defined).
Lung Cancer Stigma and the Socio-Ecological Model

(Hamann et al., 2018, Journal of Thoracic Oncology)
Survivorship Care Intervention Development: *Guiding Principles*

- **Designed for Dissemination**
  - Acceptable
  - Feasible

**Intervention Delivery**
In-person, telephone, telemedicine, other

**Interventionists**
Any survivorship care specialist identified by site

**Targeted and Tailored Content**
Lung cancer targeted
Patient/Caregiver tailored (survivor/provider)
Precision Survivorship Care

- The Kentucky LEADS Collaborative Lung Cancer Survivorship Care Program is a *Precision Medicine* approach to Survivorship.

By design, the intervention *targets* the most prevalent and distress symptoms and challenges associated with a lung cancer diagnosis.

By integrating patient preferences, the intervention is *tailored* to the unique needs of the survivor, the preferred delivery method, and the desired level of involvement of the social support network.
Patient-Centered Care Principles

- Partnering/Supportive Counseling Style
  - Rogerian/Motivational Interviewing
  - Coping with/Addressing stigma concerns

- Shared Decision Making (SDM)
  - Adaptable (targeted and tailored content) that follows from Baseline Assessment and patient preferences
  - Effort to maximize survivor acceptability of the intervention
Survivorship Care (SC)  
Patient and Caregiver Intervention

- Built and implementing a novel psychosocial survivorship care intervention for individuals diagnosed with lung cancer and their caregivers (10 sites, 300 participants)

- Four key domains
  - Lung cancer info
  - Symptom coping
  - Psychosocial concerns
  - Caregiver support
Patient Modules (Session Topics)

1) Lung Cancer Basics
2) Navigating the Healthcare System
3) Coping with Pain/Addiction Concerns
4) Coping with Fatigue
5) Coping with Sleep Problems
6) Coping with Shortness of Breath
7) Coping with Distress
8) Social Support
9) Values and Decision Making
10) Healthy Living
11) Tobacco Use

12) *Caregiver Concerns and Self-Care*

Lung Cancer Info (2)
Symptom Coping (4)
Psychosocial Concerns (5)
Caregiver Support (1)
Survivorship Care (SC)
Specialist Training Program

- A sustainable companion training program to support KY LEADS SC Specialists in their work with the program.

- Training Program
  Online CE Program
  Training Manual
  Survivor/Caregiver Workbook
Project Goals and Summary

- We hypothesize that the Kentucky LEADS Collaborative Lung Cancer Survivorship Care Intervention and Training Program will:

1) improve quality of life, better symptom control, increase tobacco treatment, and reduce distress among lung cancer survivors.

2) improve quality of life, increase tobacco treatment, and reduce distress among family members/caregivers of individuals diagnosed with lung cancer.

3) increase self-efficacy and skills in providing lung cancer survivorship care among program providers (e.g., nurses, social workers, navigators, psychologists, etc.).
Implementation Site Partners Across Kentucky

2 Academic Medical Centers
2 Large Hospitals
3 Regional Hospitals
1 Small Hospital
1 Outpatient Cancer Clinic
SC Intervention Research Plan (N=300)

- Survivors/Caregivers (N=30 per site)

  Quality of Life (multiple domains to match intervention)

  Pre, Post, 3-month follow-up

  Key Informant Interviews with subset (2 per site)
The early signal regarding intervention feasibility is also quite favorable.

The trial has been launched at 9 of the 10 sites, achieving a rate of one additional site per month.
Project Results to Date (Survivors & Caregivers)

First Lung Cancer Survivorship Trial Experience

The Kentucky LEADS Collaborative Trial

Accrual and Goal Dates
Project Results to Date (Clinicians)

**Confidence to Address Lung Cancer Survivorship Concerns**

**Statistically significant improvement across 12 of the 16 topic domains**

*SC Specialists consistently reported increased confidence to address LC Survivorship.*
Key Lessons from the Kentucky LEADS Collaborative LC Survivorship Care Study

1) Using a *precision medicine* approach to lung cancer survivorship proved efficacious in reaching and supporting individuals (survivors and caregivers) following a lung cancer diagnosis.

2) The Kentucky LEADS Collaborative Lung Cancer Survivorship Care Program Intervention was well-received by clinicians, survivors, and caregivers, demonstrating substantial feasibility and acceptability.

3) The survivorship care *specialist training platform and intervention fidelity measures were similarly well-received* (e.g., online training, treatment manuals, in-person training, and follow-up).

4) Of the 9 implementation sites, *8 remain interested in offering the intervention and collaborate on the next phase of intervention research*, with several additional sites expressing interest in collaboration (e.g., Pikeville Medical Center, Baptist Health, Paducah).
Summary

1) Lung cancer diagnosis and treatment carry substantial psychosocial and symptom burden.

2) In addition, a variety of socio-cultural issues play prominent roles in reducing social support and empathy among individuals diagnosed with lung cancer.

3) These issues have received substantially less attention from researchers, clinicians, and advocates in comparison to other malignancy populations.

4) Innovations and improvements in lung cancer care create (and even demand) a new focus on lung cancer survivorship issues that impact quality of life as well as morbidity and mortality.

5) Opportunities abound for addressing the psychosocial burden of lung cancer.
Dedicated to reducing the burden of lung cancer in Kentucky and beyond through development, evaluation, and dissemination of novel, community-based interventions to promote provider education, survivorship care, and prevention and early detection regarding lung cancer.

Connect with us:

www.kentuckyleads.org

Kentucky LEADS Collaborative

@KentuckyLEADS

KentuckyLEADS

Jamie L. Studts, PhD (Principal Investigator) jamiestudts@uky.edu

Allyson Yates (Program Director) ayates@uky.edu
Survivorship Care (SC) Team

**University of Kentucky**
- Jamie L. Studts (PI)
- Michael Andrykowski (Co-I)
- Robin Vanderpool (Co-I)
- Jessica Burris (Co-I)
- Cynthia Robinson (Co-I)
- Susanne Arnold (Co-I)
- Courtney Blair (PD)
- Amy Christian (RA)
- Allyson Yates (Project Manager)

**University of Louisville**
- Tara Schapmire (Co-I)
- Barbara Head (Co-I)

**Lung Cancer Alliance**
- Maureen Rigney (Co-I)
- Angela Criswell (KFC)
What did we do? (to improve feasibility and acceptability)

- Work to lower the barriers to participating (feasibility)
- Work to make the intervention more accessible
- Work to make the intervention more appealing (acceptability)
- Work to make the intervention more flexible (acceptability)
- Work to give participants more control (acceptability)
- Work to make the content relevant (acceptability)
- Work to integrate more support (caregiver option)
- Work to give participants more delivery options
CASE PRESENTATION
CHIZELLE ARCHIE
GCCE SURVIVORSHIP COORDINATOR
Goal is to ask questions that allow participants to share both issues/concerns they have about the topic and provide ideas or suggestions for overcoming issues (examples of what their cancer centers may have done etc.)
JOIN US FOR LUNG CANCER PATIENT SUPPORT ECHO SESSION 13
LUNG CANCER TREATMENT: ADVANCED STAGE LUNG CANCER AND END OF LIFE/HOSPICE

THURSDAY, MAY 30, 2019
9:00 AM ET

We will also be debriefing on the ECHO experience and discussing future opportunities.