



# Moving Beyond Population Averages: Patient Principles for a Personalized Medicine Research Agenda

**Webinar #1**

**October 31, 2018**

**2:00 pm - 3:00 pm EST**



# Webinar Agenda

## I. Welcome and Overview

- Welcome
- Using webinar functions
- Who are we?
- What is personalized medicine?
- What is patient-centered outcomes research?
- What is the project trying to accomplish?
- How is this project funded?
- Introduction: David LeDuc and Danielle Hicks from the Addario Lung Cancer Foundation

## II. Guest Speakers

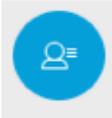
- Progress in Personalized Lung Cancer Treatment
- Disparities in Care Delivery
- Solutions and Best Practices
- Remaining Gaps in Knowledge

## III. Discussion and Next Steps



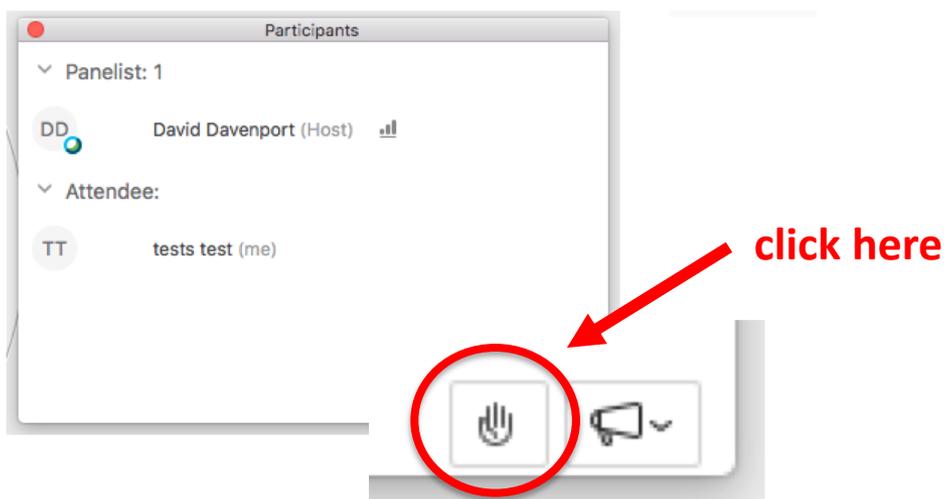
# Webinar Functions

- Your audio is muted. You will need to raise your hand to be unmuted. **To raise your hand:**

1. Open the “Participants”  feature.



2. Select the “raise your hand”  button:



# Webinar Functions

- Your video webcam will be disabled.
- Q&A and polling features are enabled. These are located in the sidebar on your screen and we will use them during the discussion period.
- The webinar will be recorded. It will be archived for future viewing and dissemination.
- If you need technical assistance, please contact the Host through the Q&A feature, or email [ddavenport@personalizedmedicinecoalition.org](mailto:ddavenport@personalizedmedicinecoalition.org).

# Who We Are



**Cynthia A. Bens**

SVP, Public Policy

Personalized Medicine Coalition  
Engagement Award Project Lead



**David Davenport**

Manager, Public Policy

Personalized Medicine Coalition  
Engagement Award Project  
Manager

# What is Personalized Medicine?

Personalized medicine, often referred to as precision medicine, is an evolving field in which physicians use molecular diagnostic tests to determine which medical treatments will work best for their patients. By combining the data from those tests with an individual's medical history, circumstances, and values, health care providers and patients can develop targeted treatment and prevention plans.



# What is Patient-Centered Outcomes Research?

Patient-centered outcomes research helps people and their caregivers communicate and make informed healthcare decisions, allowing their voices to be heard in assessing the value of healthcare options. This research answers patient-centered questions, such as:

- “Given my personal characteristics, conditions, and preferences, what should I expect will happen to me?”
- “What are my options, and what are the potential benefits and harms of those options?”
- “What can I do to improve the outcomes that are most important to me?”
- “How can clinicians and the care delivery systems they work in help me make the best decisions about my health and health care?”

Source: <https://www.pcori.org/research-results/patient-centered-outcomes-research>



# Project Overview

- We will work with you to develop a set of patient-centered principles to advance personalized medicine during four web forums over the next year.
- We will invite approximately 45 patients, caregivers, researchers and health care providers to an in-person roundtable in Washington, D.C., at which participants will translate the principles into a research agenda.
- We will publish the complete research agenda in the form of a white paper in 2020.
- The research agenda will be publicly disseminated to inform future studies that will provide patients, caregivers and clinicians with the evidence they need to make more informed health care decisions.

## Project Funding

This project was selected by the Patient-Centered Outcomes Research Institute (PCORI) to receive a Eugene Washington Engagement Award because it will establish partnerships and build a community equipped to participate as partners in advancing patient-centered clinical effectiveness research.



# Guest Speakers



**David LeDuc**

Executive Director

Bonnie J. Addario Lung Cancer  
Foundation



**Danielle Hicks**

Associate Executive Director of  
Patient Services and Programs  
Bonnie J. Addario Lung Cancer  
Foundation

# Personalized Medicine Coalition

Webinar Series

October 31, 2018



BONNIE J. ADDARIO  
**LUNG CANCER**  
FOUNDATION

## Who We Are...



BONNIE J. ADDARIO  
**LUNG CANCER**  
FOUNDATION

### ***Transform lung cancer into a chronically managed disease***

- Increasing early detection
- Improving consistency and quality of care
- Increasing treatment options and effectiveness
- Providing patient support and education





# What is Personalized Medicine and how is it Transforming Cancer Care?

Personalized Medicine is Transforming how patients with Lung Cancer are being treated

Screening/Early Detection  
Multi-Disciplinary Teams – Tumor Boards  
Molecular Testing – Targeted Therapy  
PD1/PDL1 Testing – Immunotherapy  
TMB  
Combination Therapies  
Clinical Trials  
Supportive Care  
Survivorship - Education and Support

Educated and Empowered patients live longer.

## Reaching the Unreachable

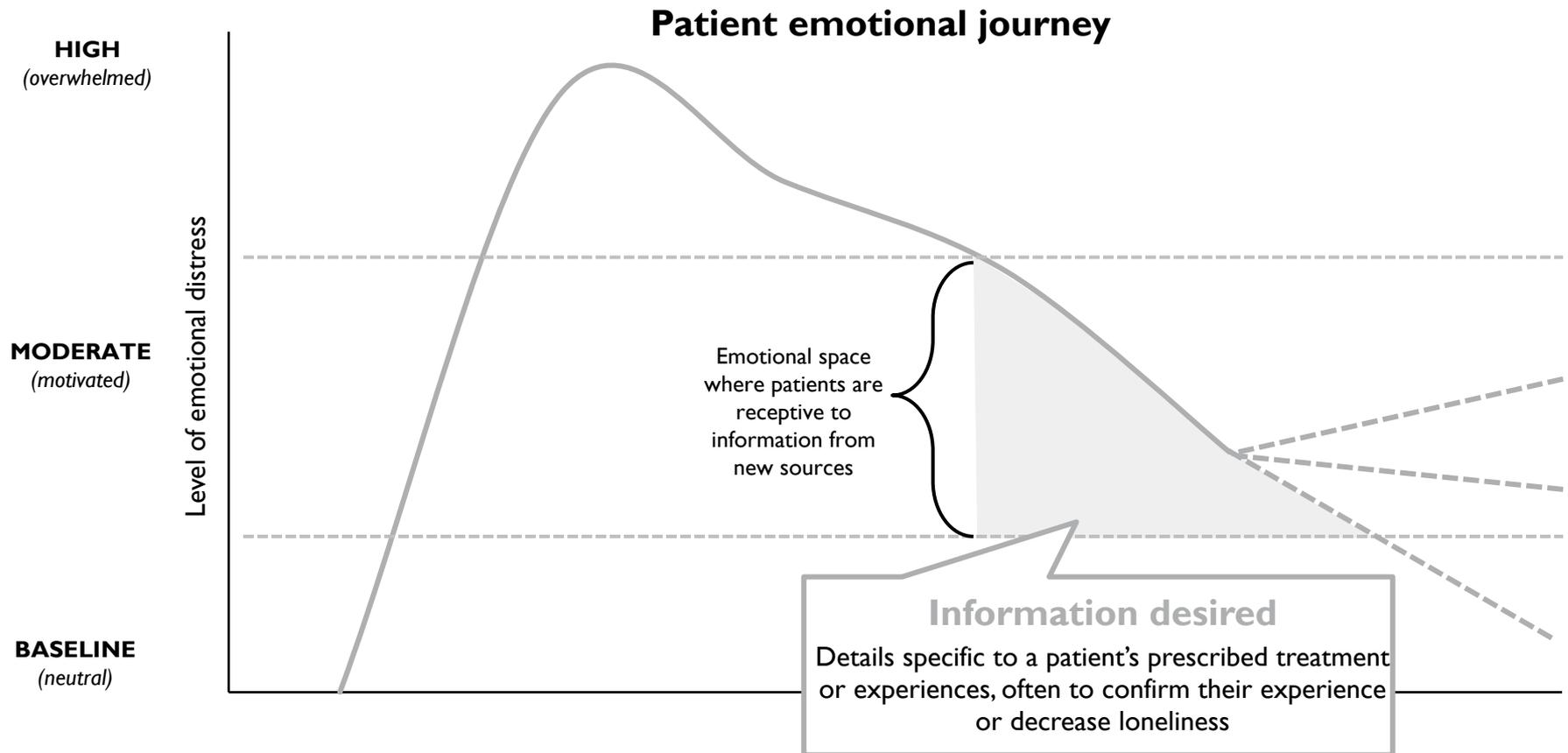
ZS Associates – market research

Objective



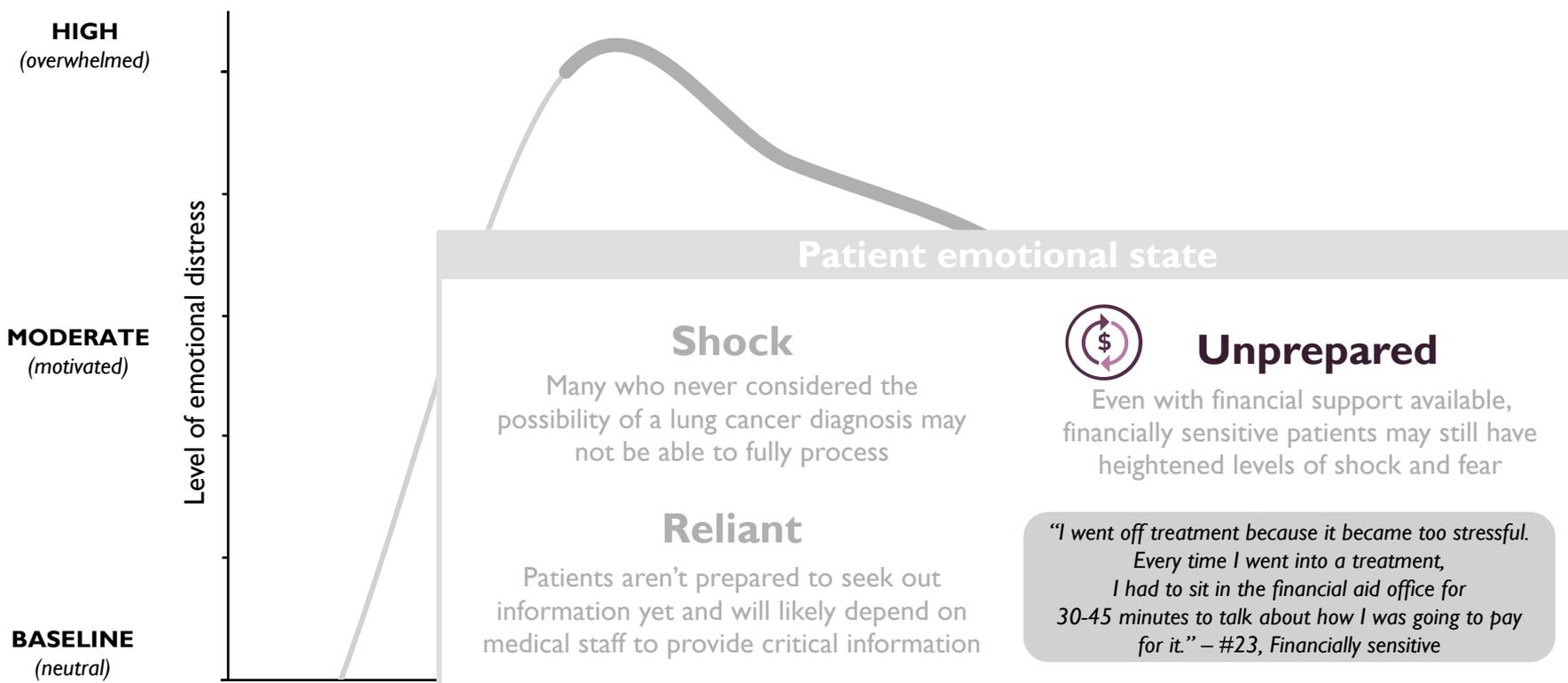
To identify key barriers to reaching lung cancer patients who have limited engagement with their treatment and limited knowledge about precision medicine

# When are patients most receptive to care?





At diagnosis, patients have the most questions around lung cancer but may feel too distressed to know where to find that information





At diagnosis, patients have the most questions around lung cancer but may feel too distressed to know where to find that information



**HIGH**  
(overwhelmed)

Level of emotional distress

**MODERATE**  
(motivated)

**BASELINE**  
(neutral)

How can ALCF help patients move from shock to empowerment?  
 How can ALCF position itself as a key resource once a patient emerges from the "diagnosis fog"?

**Patient emotional state**

<p><b>Shock</b></p> <p>Many who never considered the possibility of a lung cancer diagnosis may not be able to fully process</p>	<p><b>Unprepared</b></p> <p>Even with financial support available, financially sensitive patients may still have heightened levels of shock and fear</p>
<p><b>Reliant</b></p> <p>Patients aren't prepared to seek out information yet and will likely depend on medical staff to provide critical information</p>	<p><i>"I went off treatment because it became too stressful. Every time I went into a treatment, I had to sit in the financial aid office for 30-45 minutes to talk about how I was going to pay for it." – #23, Financially sensitive</i></p>

- Older smoker
- Financially sensitive
- Untreatable patient
- Male

# Patients primarily depend on their medical staff for information at diagnosis, using the internet to supplement their understanding of basics



## Trusted sources

## Patient interaction

## Unmet need

## ALCF opportunity

### Medical staff



- Patients depend on medical staff to provide most information
- “Doctors are the first line to let people know about the cancer. They can let the patient know there are places you can go if you have questions.” – #24, Older smoker*
- Many are too overwhelmed to question doctor’s credibility



**Moderate**

Patients trust their doctors, or are willing to switch to find a better fit but fear “bothering” doctors with questions

- Increase awareness of ALCF programs through MD referral
- Summarize important topics to help patients know what to ask MDs
- Make clear that ALCF supplements MD visits

### Online



- Patients enter basic search terms on lung cancer, to better understand their diagnosis and doctor appointment



**Low**

Many online sources can answer basic questions but may not be updated

- Expand ALCF visibility within online searches
- Cross-promote ALCF programs to help patients discover helpful resources

COE referrals to ALCF will be most influential at diagnosis, as patients depend on medical staff for initial lung cancer information



Patients primarily depend on their medical staff for information at diagnosis, using the internet to supplement their understanding of basics



Trusted sources

**Medical staff**

**Online**

Patient interaction

- Patients depend on medical staff to provide most information
- Many are too overwhelmed to question doctor's credibility

*"Doctors are the first line of defense for the cancer. They can let you know where are places you can go to get help."*  
#24, Older adult

Unmet need

- Frame ALCF as an additional resource to best utilizing the time and care from physicians
- Promote ALCF through nurse navigators, pulmonologists, PCPs

...but fear "bothering" doctors

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- Guide patients through website content with clear sections (e.g., Newly diagnosed? Questions about second opinions?)
- Enhance search engine optimization of ALCF

...may not be updated

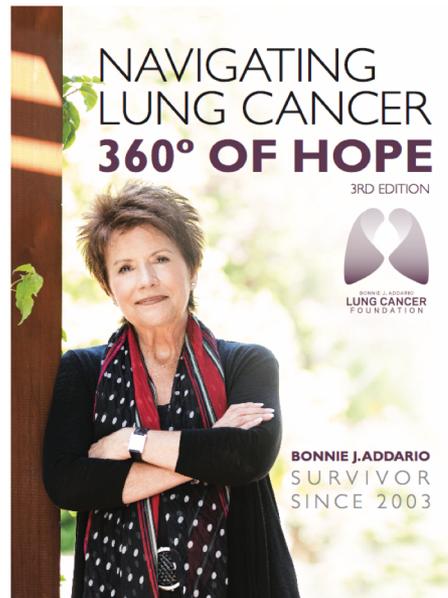
ALCF opportunity

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- Expand ALCF visibility within online searches
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COE referrals to ALCF will be most influential at diagnosis, as patients depend on medical staff for initial lung cancer information

- Overview:
  - Comprehensive patient handbook from diagnosis through late stage treatment
  - Expertly vetted by KOLs and updated frequently to include the latest FDA approvals
  - Serves as an important tool for the navigator and physician staff
- Goals/Objectives
  - Every diagnosed patient should have a handbook
  - Every nurse navigator using the handbook

*“I just wanted to thank you for the Addario book you gave me. **There was so much information in there that helped clarify everything for me, and I truly appreciate it. I read through it twice (in one day) and plan on looking it over again once I get home. I really liked having something in my hands that I could look through to help me get answers.**” (Lung Cancer Patient)*



*“I appreciate your assistance and the resource you provide. I know my patients appreciate seeing Bonnie’s picture on the cover. **I make it a point to share her story with each patient to instill a sense of hope in them.** I think it makes a difference knowing that someone has been where they are, cared enough to step-in and provide this resource, and has been a survivor for nearly 15 years – **I enjoy seeing their faces light up when they understand there is always hope!**” (COE Nurse Navigator)*



## Addario Lung Cancer Foundation Patient Education Handbooks Fill a Health Literacy Void for Patients and Nurse Navigators

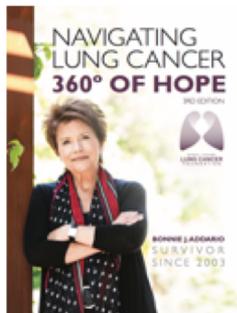
Leah Fine MBA, Danielle Hicks, David LeDuc: Bonnie J Addario Lung Cancer Foundation  
Steven Young: Addario Lung Cancer Medical Institute (ALCI)

Abstract #10444  
Contact: Leah@lungcancerfoundation.org

### Background

A lung cancer diagnosis is devastating and patients are often left in shock and seeking trusted resources. The Bonnie J. Addario Lung Cancer Foundation (ALCF) provides patient education and support resources, including the patient education handbook.

The handbook is a comprehensive resource on lung cancer presented in an easy-to-navigate format, written for the general public, produced in multiple languages and updated to keep pace with emerging advancements. Previous studies have shown that health literacy is correlated with patient engagement and outcomes. The handbook fills the void for patients by providing physician-vetted information on topics related to living with lung cancer including diagnosis and treatment options.



### Methods

Two studies were conducted to assess the value of the handbook to patients and nurse navigators.

**Study 1 Patients:** The first study was a qualitative market research study that included a total of *26 patient interviews*, conducted by an independent market research firm in a blinded format. Patients in this study did not have prior exposure to ALCF. Patients rated several ALCF support resources on a scale from 1 to 5, with "1" being "not appealing at all" and "5" being "very appealing."

**Study 2 Nurse Navigators:** The second study was the COE Impact Study which assessed the *usage, value and timing of the patient education handbook resources by the ALCF Centers of Excellence (COE) members* (a network of community hospitals) through a quantitative online survey.

### What Patients Had to Say

Patients commented that the handbook is a *"one-stop-shop"* for everything they need to know about a lung cancer diagnosis.

It delivers information in a straightforward way, mapping out treatment options and next steps and empowering patients to help them manage side effects and related lifestyle issues.

Patients noted it would be most valuable to have at the time of diagnosis but that it can help at any point in their patient journey.

*"The handbook would be most useful at diagnosis, you have a million questions and you are so overwhelmed"*

*"Right now, there is no help, I'm on my own"*

*"This is a one-stop-shop for everything I need to know at a lung cancer diagnosis"*

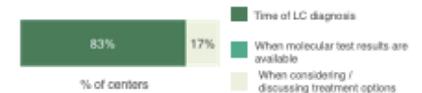
*"This can help me at any point in my patient journey"*

*"It would have been fantastic to have this handbook...it provides many avenues to know about lung cancer and how to talk to your doctor...I would raise questions from it even if it contradicted my doctor"*

### Study 2 Results: Navigators

All of the COEs who provided ALCF materials to their patients (6/11), utilized the handbooks and viewed it as the most valuable tool for their patients. Of those COEs not actively using ALCF materials, most (>70%) indicated they would like to implement the handbook.

#### Timing of ALCF Material Usage



83% of nurse navigators rely on the handbook at the time of diagnosis. The remaining use it as part of the treatment options discussion.

### Study 1 Results: Patients

Patients rated all ALCF programs highly, scoring each program based on how well they could see these programs fitting into their patient journeys.



Most patients see the handbook as a comprehensive guide through the lung cancer patient journey and rated it 4.4/5 in value to patients.

### Conclusions & Opportunities

The patient education handbook is a valuable tool for patients and nurse navigators, especially at diagnosis when the need for trusted information is greatest.

Opportunities exist to continuously improve the patient education handbook, including: reformatting it to be modular; coaching patients on how to use the information to dialog with their physicians; expanding usage within the COEs and training nurse navigators on how to use the book with patients.

Future studies may explore how patients and nurses work together with the handbook throughout the patient journey. ALCF hopes to reach and empower as many lung cancer patients as possible with valuable and accessible information that will guide their treatment journey.

# Lung Cancer Living Room: Empowering Patients with Hope and Education

- Patient Empowerment and Hope:
  - To **educate and empower** patients and to make informed decisions regarding their treatment options and maintain quality of life
  - To **learn from Expert Guest Speakers and support one another** by sharing stories and engaging in hopeful conversation in an open and honest forum





# Lung Cancer Living Room: Empowering Patients with Hope and Education



## BRING HOPE HOME

a patient education and support series

### LUNG CANCER LIVINGROOM

#### JOIN US! LIVE

Whether you join us in the Bonnie J. Addario Lung Cancer Foundation's (ALCF) Living Room or attend remotely through the live stream on your computer, you will be informed about living with lung cancer.

3<sup>rd</sup> Tuesday of every month  
Dinner: 5:00 PM Pacific  
Program: 5:30 – 7:30 PM Pacific

**In Person at Our Living Room**  
1100 Industrial Road, #1  
San Carlos, CA 94070

**Online via YouTube**  
[www.youtube.com/user/BonnieJAddario](http://www.youtube.com/user/BonnieJAddario)

**Jan 16<sup>th</sup>**  
*Living With Lung Cancer: A PATIENT PERSPECTIVE*  
Anne Marie Cerato, Lisa Goldman, Dave Karlin, Jessica Steinberg, Don Stranathan and Dr. Deborah Morosini

**Feb 20<sup>th</sup>**  
*Oncology Financial Navigation*  
Clara Lambert- Association of Community Cancer Centers (ACCC)

**Mar 20<sup>th</sup>**  
*Legislation/Policy and Lobbying*  
Laurie Fenton and Elridge Proctor with Lung Cancer Alliance (LCA), Patient/Caregiver Francis and Roslyn Spruit

**April 17<sup>th</sup>**  
*Immunotherapy/Combo Therapies*  
Dr. Jack West - Swedish Medical Center

**May 15<sup>th</sup>**  
*Your Cancer Game plan. Building your team*  
Survivor - Taylor Bell, North Carolina

**June 19<sup>th</sup>**  
*Resistance to Targeted Therapies*  
Dr. Colin Blakely - University of California San Francisco Medical Center, Survivor - Teri Kennedy

**July 17<sup>th</sup>**  
*Best of ASCO ( American Society of Clinical Oncology)*  
Dr. Hatim Hussain - UC San Diego Health, Amy C. Moore Ph.D - ALCF, Director of Science and Research

**August 21<sup>st</sup>**  
*Advances in Molecular Based Therapy*  
Dr. Heather Wakelee - Stanford Health Cancer Center

**September 18<sup>th</sup>**  
*Making Sense of Immunotherapy for Lung Cancer*  
Dr. David Gandara - UC Davis Cancer Center

**October 16<sup>th</sup>**  
*A Discussion on Different Types of Clinical Trials and Why it is Important*  
Dr. Jacob Sands - Dana-Farber Cancer Institute

**November 13<sup>th</sup>** (please note date change due to Thanksgiving holiday)  
*Expanding the Benefits of Tumor Boards to Patients*  
Dr. Laurence Hellefetz - Gene Upshaw Memorial Tahoe Forest Cancer Center

**December 18<sup>th</sup>**  
*Patient Roundtable/Holiday Celebration*



## REGIONAL SERIES

## BRING HOPE HOME

a patient education and support series

### LUNG CANCER LIVINGROOM

#### LIVING ROOM ON LOCATION

We're taking the show on the road! In order to try to reach even more people around the country, we're taking our patient-focused mission to a city near you. As always, you can also join us online through the live stream. We hope to see you soon!

Dinner: 5:00 PM Local Time  
Program: 5:30 – 7:30 PM Local Time

#### JOIN US! LIVE

**In Person at Our Living Room**  
For the location for each event, check our website at  
<https://www.lungcancerfoundation.org/patients/support>

**Online via YouTube**  
[www.youtube.com/user/BonnieJAddario](http://www.youtube.com/user/BonnieJAddario)



**April 5<sup>th</sup>**  
Columbus, OH  
Dr. David Carbone - Ohio State University  
Dr. Carolyn Presley-Ohio State University

**April 9<sup>th</sup>**  
Memphis, TN  
Dr. Raymond Osoarogabgon - Baptist Cancer Center  
Leah Fine - Director of Centers of Excellence at ALCF  
Gina Hollenbeck - Survivor

**May 10<sup>th</sup>**  
Chicago, IL  
Dr. Timothy Kruser - Northwestern University  
Dr. Christopher Seder - Rush University  
Dr. Nisha Mohindra - Northwestern University

**August 2<sup>nd</sup>**  
Hollywood, FL  
Dr. Luis Raez - Memorial Cancer Institute  
Dr. Ana Botero - Memorial Cancer Institute  
Dr. Mark Block - Memorial Cancer Institute  
Dr. Estelamari Rodriguez - Mt. Sinai

**August 6<sup>th</sup>**  
Denver, CO  
Dr. Ross Camidge - University of Colorado  
Dr. Dara Aisner - University of Colorado  
Dr. Chad Rushhoven - University of Colorado

**November 6<sup>th</sup>**  
Chicago, IL  
Dr. Jessica Donington - University of Chicago  
Dr. Jyoti Patel - University of Chicago  
Dr. Kyle Hogarth - University of Chicago  
Livia Szeito, RN - Research Nurse, University of Chicago

**Date TBD**  
Los Angeles, CA  
Speaker TBD

- **Overview:**
  - Personal guidance and support offered free of charge to patients
  - ALCF navigation augments cancer center's capabilities by helping to ensure patients are empowered to work with MDT and navigation staff
  - Resources to help Navigation staff address their program's development and enhance utilization patient resources
  - Experience working with hundreds of patients and driving for program results
- **ALCF Navigator Team**
  - Kim Parham RN, BSN
  - Michele Zeh
  - Danielle Hicks

# The Lung Cancer Registry: Patient Voices and Outcomes Driving Discoveries



- **Overview:**
  - Patient registries offer a **secure way** for the patient voice and experience to be leveraged by the broader patient population and medical community
  - The Lung Cancer Registry hopes to accelerate discoveries while giving patients a voice
  - Clinicians and researchers benefit by having access to aggregated data in a searchable research tool and reports on emerging trends
  - Ability to create & run clinician-driven studies available through proposal submissions
- **Highlights:**
  - 958+ patients in more than a dozen countries since its inception in 2017
  - Launched first registry study in January 2018, “*Immunotherapy PRO*” in partnership with Thomas Jefferson University and the Moffitt Cancer Center and Research Institute
  - Launching RFP in 2019 to drive further partnership with COEs and develop studies using patient reported data



## Lung Cancer Patients to Help Medical Community Understand the Side Effects of Immunotherapy Treatment

- Study designed to validate a patient-reported outcome symptom measure for NSCLC patients treated with immunotherapy to enable physicians to educate patients and set appropriate expectations for this new therapy
- Study funded through 2019
- 158 Completes registered in study. Goal is 200
- Partners can help by encouraging patients on immunotherapy treatment to participate in the study

# COE Impact Study: “What good looks like”

- **Overview:**
  - Data tool to comprehensively assess the lung cancer care continuum
  - Comparative analysis creates opportunity for shared learning and quality improvements
- **Goals/Objectives/COE strategy**
  - Participation and engagement from all COEs to make data valuable and generate meaningful insights
  - Build a statistically significant sample set with longitudinal trend data
  - Data that illustrates “what good looks like” and ability to influence guidelines and standards
- **Collaborations & Successes**
  - Presented at IASLC World Lung
  - Publication in JTO 2017
  - Adopted framework for how data is collected at Dignity Mercy San Juan
  - COEs connecting with and learning from other COEs - **Summit December 5-7, 2018**
- **COE Impact Study Implementation**
  - Annual survey launched in June/July timeframe
  - Survey preparation begins April
  - 2018 Results coming November 2018

COE suspicious nodule follow up is more common in COE than non COE  
47% vs 27%

COE's utilize more NGS and blood based biopsy than non-Coe's  
NGS 79% vs 58%  
Liquid 74% vs 18%

COE's more commonly test for PDI/PDLI  
79% vs 61%

COE's have increased numbers of palliative/supportive care discussions  
80% vs 62%

COE more likely to be set up to participate in clinical trials than non COE's  
80% vs 47%

COE Clinical Trial enrollment vs non COE  
89% vs 70%

Most Common reason patients are not molecularly tested is biopsy fail  
38% and 33%

# Thank You

## Q&A

# Discussion

1. In your disease area, is there a personalized medicine/targeted treatment strategy? Yes or No.
  
2. Prior to diagnosis, did you know that there were targeted treatments/personalized medicine treatment strategy for your disease? Yes or No.
  
3. How did you find out about the targeted treatments/personalized medicine treatment strategy before your diagnosis?
  - A. TV, Magazine or Internet advertisement
  - B. WebMD, the National Institutes of Health, the Food and Drug Administration, or similar website
  - C. A patient advocacy organization
  - D. Another patient with the disease

# Discussion (Continued)

4. Are there challenges with access to targeted treatments/personalized medicine for your disease that are similar to those described by our guest speakers from the lung cancer community? Yes or No.
5. Is there research or advocacy efforts in place to overcome these access challenges? Yes or No.
6. What do you believe is most important for your doctor to consider when treating you with a personalized medicine strategy?
  - A. Your biology
  - B. Your values
  - C. Your circumstances

# Discussion (Continued)

7. Thinking of what you identified as important considerations for your doctor in treating you, would the research agenda be most helpful if questions targeted –
  - A. Ways for communicating additional information on **biological differences** that allow for informed decision-making
  - B. Identifying and communicating treatment options based on **patient/caregiver values**
  - C. Understanding **patient/caregiver circumstances** and presenting treatment options in ways that highlight how a treatment aligns/does not align with those circumstances

# Next Steps

- We will take feedback from this program and use it to inform our next webinar. Target timeframe for that webinar is mid-late January 2019.
- You will receive an evaluation survey for this webinar. We would encourage you to fill it out so that we can see how we did and how we can improve the next webinar.
- Post webinar archive and slides. These will be available on PMC's website, [www.personalizedmedicinecoalition.org](http://www.personalizedmedicinecoalition.org)
- Continue outreach. If there are individuals or organizations you feel would benefit from this program, please let us know.
- If you have an idea, stay in touch!

Thank you for your attention.  
Questions or comments, please contact us.

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