

# ADDRESSING LUNG CANCER STIGMA

Katherine Pruitt  
National Assistant Vice President of Health Education

April 13, 2016

# ABOUT THE AMERICAN LUNG ASSOCIATION



**Our Mission:** To save lives by improving lung health and preventing lung disease.

**Our Vision:** A world free of lung disease.

**Our Strategic Imperatives:**

- **Defeat lung cancer.**
- **Reduce the burden of lung disease on individuals and their families.**
- Improve the air we breathe so it will not cause or worsen lung disease.
- Eliminate tobacco use and tobacco-related diseases.
- Monitor and enhance organizational effectiveness.

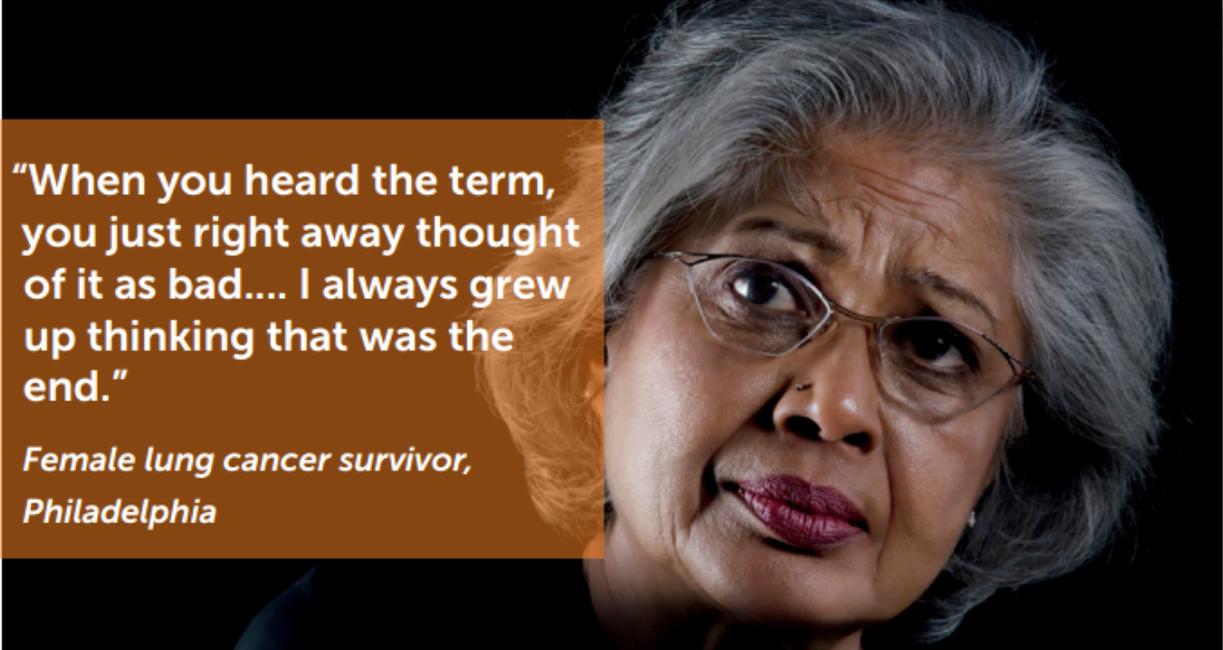
# OVERVIEW OF STIGMA RESEARCH

- Large market research study on knowledge and attitudes of general public
- Large survey to lung cancer patients/loved ones
- Multiple focus groups with the general public, lung cancer patients and lung cancer caregivers/loved ones
- Series of stakeholder interviews
- Survey of Lung Association staff and volunteers
- Comprehensive review of existing published literature



# CAUSES AND IMPACTS

- Reasons lung cancer is stigmatized:
  - Strong connection to smoking (perceived personal responsibility)
  - Low survival rate (perceived as a death sentence)
- Impacts of lung cancer stigma
  - Emotional distress
  - Delayed diagnosis and treatment
  - Poorer quality of treatment
  - Fewer advocates
  - Division within the lung cancer community
  - **Barrier to empowering patients to be advocates and get the care they want and need**



**"When you heard the term, you just right away thought of it as bad.... I always grew up thinking that was the end."**

*Female lung cancer survivor,  
Philadelphia*

# POSITIVE OUTCOMES OF REDUCING STIGMA



- Better patient/provider relationships
- Better patient outcomes
  - Less distress
  - More likely to seek treatment, ask about clinical trials and tumor testing, get lung cancer screening
- A more robust advocacy community
  - Community is united
  - More current/former smokers likely to get involved
- More financial support for lung cancer

**Awareness and small changes in the approach to your work will have big impacts over time!**

# EMERGING BEST PRACTICES FOR REDUCING STIGMA

- Avoid:
  - Over-emphasis on smoking status when sharing patient's stories
  - Anti-stigma campaigns
- Put faces to the disease
- Educate about other risk factors
- Emphasize hope
- Encourage actions that improve self efficacy



"You can't change beliefs. You have to change experiences."

*Lung cancer stakeholder*

"Exposure to people with lung cancer and those who love them humanizes the disease."

*Lung cancer stakeholder*

# WHAT ARE WE DOING?

- Offer a variety of resources to help empower and support patients
  - Videos/downloadable resources on treatment options, communicating with care team and screening
  - Lung Cancer Action Guide
  - Lung Cancer HelpLine
  - Lung Cancer Survivors Online Support Community
- Large strategic cause campaign to raise awareness called LUNG FORCE
- Continued research around messaging to reduce stigma



# LOOKING TO THE FUTURE

- Current research to inform message training for Lung Association staff, volunteers and spokespeople
- Widespread implementation of best practices across organization and hopefully others
- Future research



# USEFUL LINKS

- [www.lung.org/lungcancer](http://www.lung.org/lungcancer)
- [www.lung.org/stigma-report](http://www.lung.org/stigma-report)
- [www.LUNGFORCE.org](http://www.LUNGFORCE.org)
- [www.lung.org/lungcancerguide](http://www.lung.org/lungcancerguide)
- [www.lung.org/lcscreening](http://www.lung.org/lcscreening)

