

ADDRESSING LUNG CANCER STIGMA

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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.

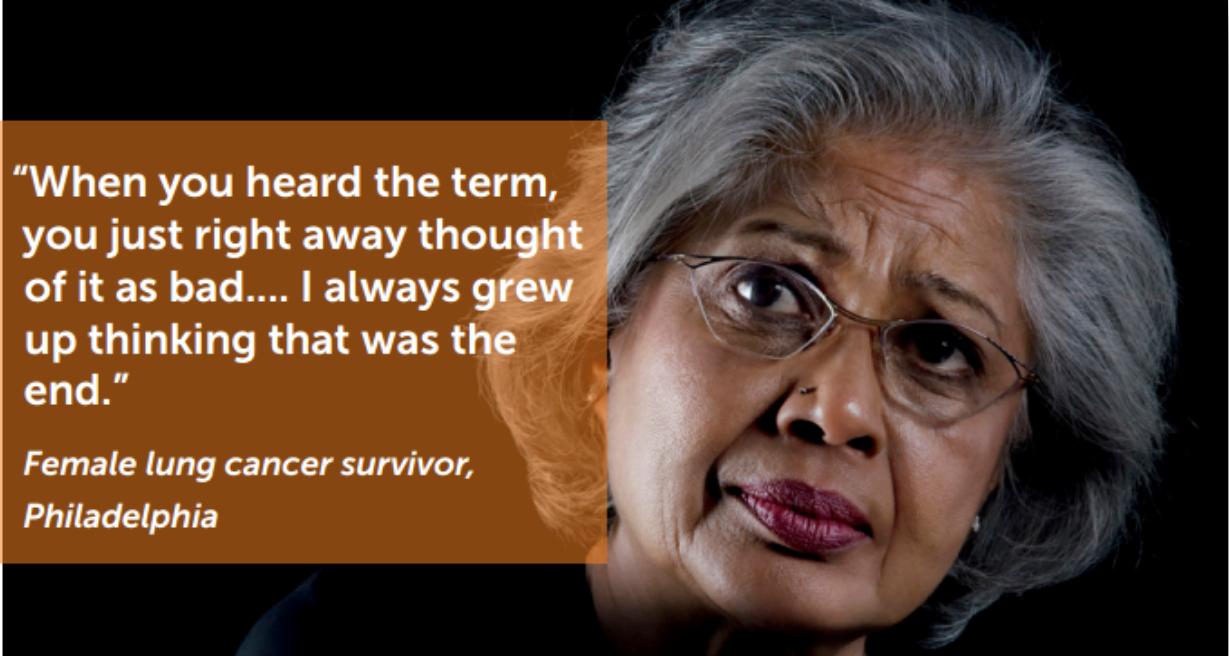
OVERVIEW OF STIGMA RESEARCH

- 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."

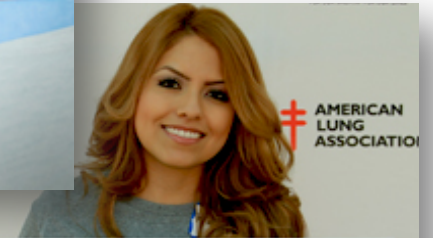
Lung cancer stakeholder

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

Lung cancer stakeholder

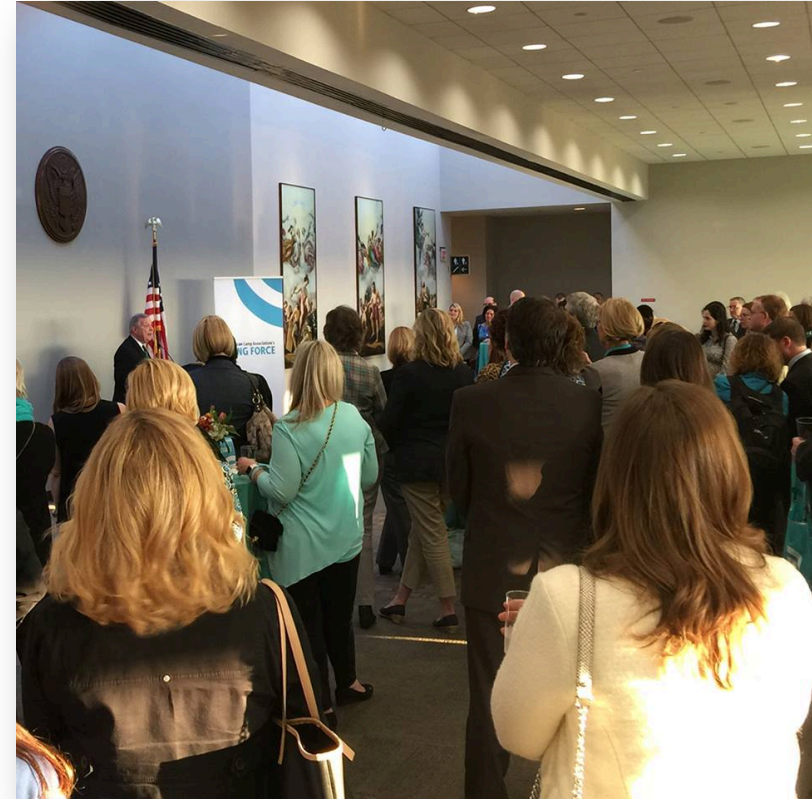
WHAT ARE WE DOING?

- 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
- www.lung.org/stigma-report
- www.LUNGFORCE.org
- www.lung.org/lungcancerguide
- www.lung.org/lcscreening

