
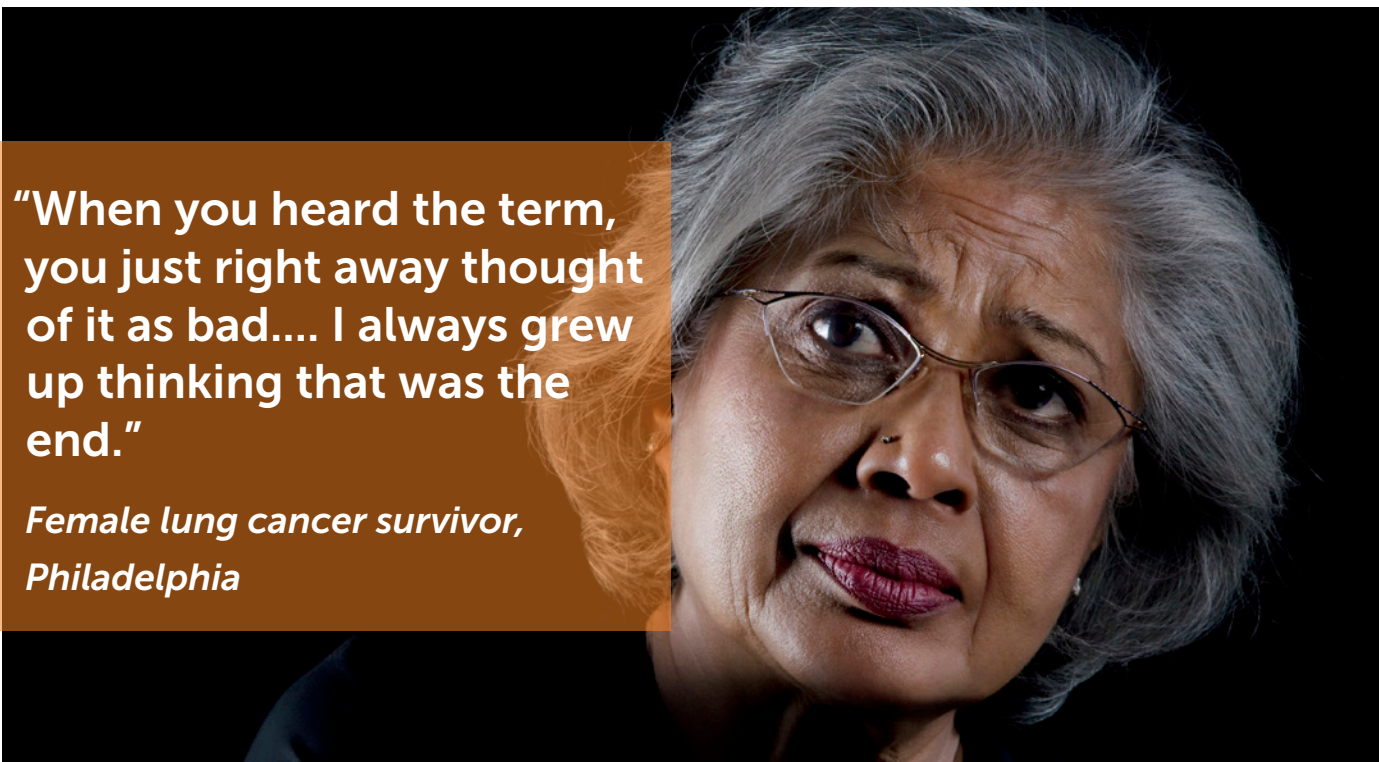




Addressing the Stigma of Lung Cancer

 **AMERICAN
LUNG
ASSOCIATION.**
Fighting for Air



“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*

Lung cancer is the leading cancer killer of both men and women in the United States, causing more deaths each year than colon, breast and prostate cancers combined. Yet awareness of this fact is low, and lung cancer does not have nearly the resources, support and public empathy that many other diseases have. This is likely due in large part to the strong, pervasive stigma associated with lung cancer. Sadly, stigma plays a major role in the lung cancer experience for most people struggling with this terrible disease. Feelings of fear, guilt and blame affect their quality of life and quality of care. Stigma is clearly linked to disease-related distress and poor health outcomes in lung cancer patients.¹

The existing body of research on lung cancer stigma is small but has shed some important light on what is a multifaceted and complex issue. The American Lung Association is committed to better understanding the scope of lung cancer stigma and to finding ways to reduce it. Since 2012, the Lung Association has conducted several opinion research projects, including an online survey, focus groups and stakeholder interviews with professionals working in the fields of lung cancer and health-related stigma. Research topics included assessing the public’s knowledge, attitudes, underlying motivations, perceptions and experiences with the

issue. What follows is an explanation of stigma and lung cancer, including causes, challenges and impact, as well as ways to address stigma and recommended next steps.

WHAT IS STIGMA?

Stigma is defined as a mark or a brand of disgrace associated with a particular circumstance or quality. Individuals and groups are stigmatized when they are judged negatively or experience discrimination because of some personal characteristic or behavior. Stigma affects a number of diseases, especially those that are feared or misunderstood, such as mental illness, epilepsy, tuberculosis and HIV/AIDS. The personal and public health consequences of health-related stigma are remarkably similar across many disease conditions and cultures.² These can include:

- avoidance or delay in seeking treatment or a second opinion;
- increased illness-related distress;
- relationship conflict;
- lack of illness disclosure;
- reduced social support; and
- lower quality of care.^{3,4,5}

Stigma can be characterized as internal, often called *perceived* or *felt* stigma, and external or *enacted* stigma. Perceived stigma is the feeling that people living with the disease have of self-blame, guilt, shame and regret. Enacted stigma is actual discrimination, intentional or not, directed at the patient and the disease by the public, healthcare professionals, family and friends or institutions.⁶ Unfortunately, stigma is a deeply held belief for many and can be difficult to change.

WHY IS LUNG CANCER STIGMATIZED?

As with other stigmatized diseases, there are multiple factors that contribute to the ways that patients, clinicians and the general public view lung cancer.

The “Invisible Cancer”

How can the leading cancer killer be called the “invisible cancer?” There are several contributing factors:

Low survival rate

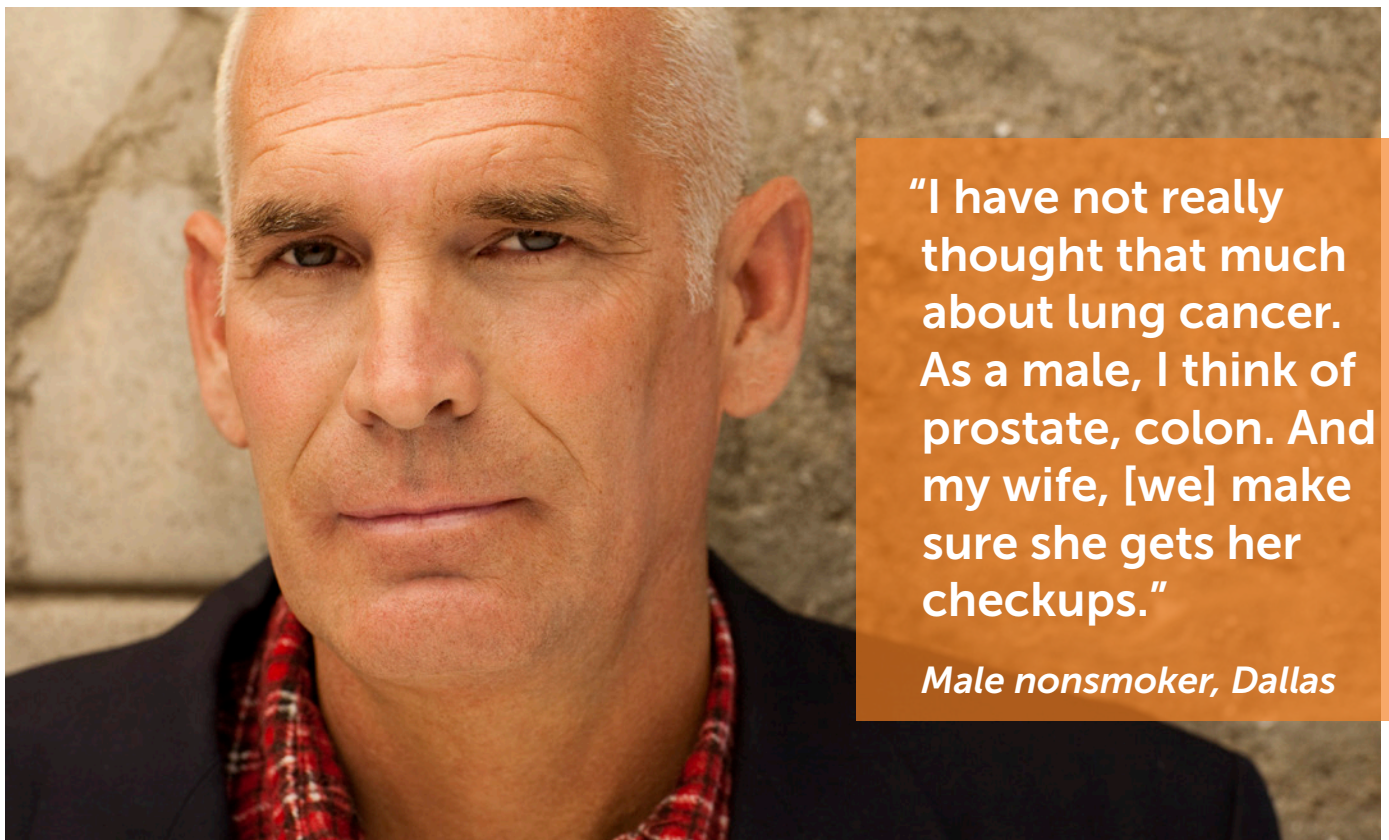
Lung cancer is a very deadly disease. Over half of people with lung cancer die within one year of being diagnosed. Only 16 percent of patients diagnosed with

“Lung cancer beats them all combined? I am very surprised! . . . I did not know it was [the] number one [killer].”

Male smoker, Dallas

lung cancer are still alive after five years, compared with over 90 percent of breast and prostate cancer patients.⁷ The low survival rate contributes to perceptions that this disease is a “death sentence.” This results in a very negative, hopeless view of lung cancer and people are uncomfortable engaging in discussions about it.

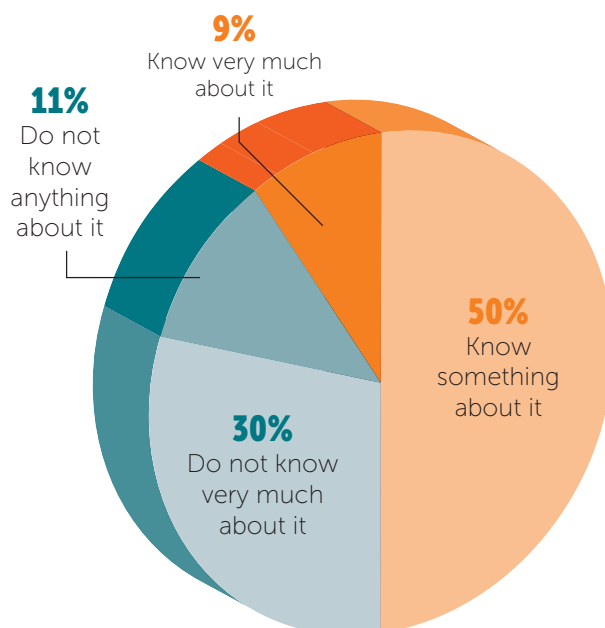
The other significant consequence of the low survival rate is that, unlike breast and prostate cancer, there is no “army” of survivors and people living with lung cancer who can become the public face of the disease, advocating for more public attention, better treatments and hope.



“I have not really thought that much about lung cancer. As a male, I think of prostate, colon. And my wife, [we] make sure she gets her checkups.”

Male nonsmoker, Dallas

Figure 1: Perceived knowledge about lung cancer



Late onset of symptoms

Symptoms of lung cancer usually do not become apparent until the cancer is in late stages, when lung cancer is harder to treat. This makes it hard to detect early and contributes to the low survival rate and the helplessness many feel when speaking about the disease.

Lack of knowledge about lung cancer

The American Lung Association's 2012 opinion research revealed that awareness of lung cancer is high but there are some significant gaps in knowledge that may impact public attitudes. The majority of people surveyed responded that they knew something about lung cancer, but only 9 percent felt they knew very much about it (Figure 1). Additionally, focus groups revealed specific areas where respondents did not have a clear understanding of lung cancer, including:

- the magnitude/numbers of lung cancer cases and deaths;
- the low levels of current funding for research; and
- the relative impact of smoking versus other causes.⁸

Little opportunity for self-efficacy and empowerment

Self-efficacy is a person's judgment about their own ability to perform a particular activity. It is essentially the opposite of hopelessness. It is important because

increasing someone's perception of control of their health – things that person can *do* – increases their engagement with the community and overall attention to the disease.

Until very recently, most self-efficacy messages for lung cancer have centered on prevention, with quitting smoking or never smoking being the most prominent prevention actions. If a person has already quit smoking or doesn't smoke, then what? Other ways to prevent lung cancer are less publicized and may not even be fully understood by the scientific community at this time. Unlike other diseases for which early detection methods are well known and widely practiced, early detection screening for lung cancer has only recently been proven effective and recommended, and only for a select group of people at high risk.

Tobacco Use and Perceived Personal Responsibility

Over 50 years ago, lung cancer became the first health risk to be conclusively linked to smoking. Since then, decades of anti-tobacco campaigns have saved hundreds of thousands of lives. They have also been highly successful in cementing the connection between smoking and lung cancer in the public's mind. Given the critical public health benefits of tobacco-use prevention and cessation, that link should not be minimized or downplayed. But it is important

to recognize that an unintended consequence has been the labeling of lung cancer as a “smoker’s disease” and the damaging perception that people with lung cancer have brought it upon themselves.

The success of the tobacco control movement has changed the way the public views people who smoke. Increased social unacceptability of smoking has contributed to the formation of a smoker stigma, and to smokers being viewed as outcasts.⁹ This, combined with the lack of understanding about addiction and poorly publicized information on other causes of lung cancer, has resulted in people with lung cancer feeling blamed for their disease, whether or not they have a history of smoking.

According to the American Lung Association’s opinion research, most people want to appear compassionate and do not identify with blame statements. However, many agree with statements that indicate patients have personal responsibility for lung cancer. (Figure 2).

THE IMPACT OF LUNG CANCER STIGMA

Stigma negatively affects every facet of the lung cancer community from patients and caregivers to physicians, researchers and funders. This makes lung cancer stigma particularly hard to address. The effects of stigma are real, especially for lung cancer patients. Research shows stigma appears to be experienced more by lung cancer patients than by other patient groups; and more by smokers compared to nonsmokers.¹ Fear of being denied treatment, concealment of

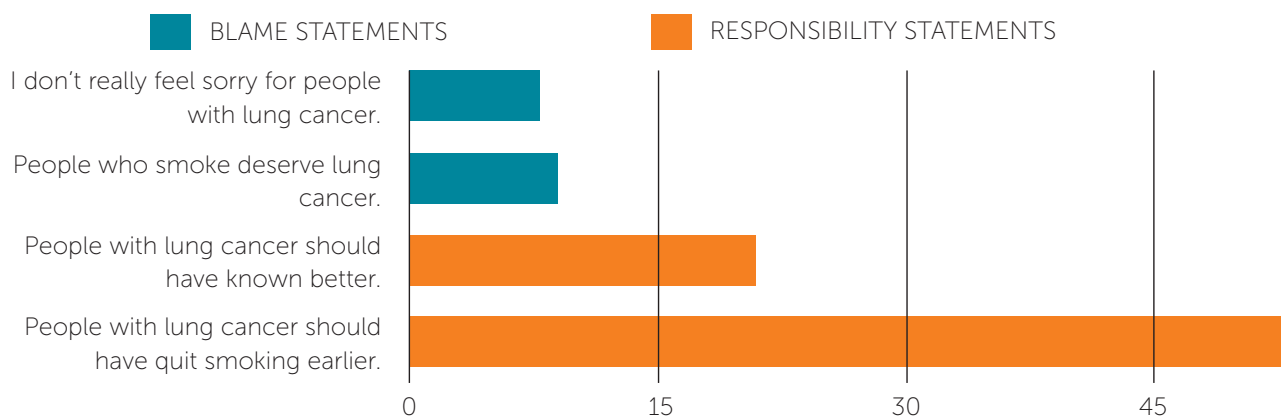
“I am surprised at the lack of research.”
Female smoker, Dallas

their condition and psychosocial distress such as anxiety, depression and isolation are all negative impacts of stigma that affect lung cancer patients.⁶

More research is needed to determine the true effect of stigma on healthcare providers and, consequently, how they interact with patients. There is little direct evidence that providers withhold treatment, however lung cancer patients clearly perceive bias, judgment and differential treatment from their providers. Additionally, there are more robust clinical guidelines for non-stigmatized cancers like breast cancers and clinicians encourage more comprehensive diagnostics and treatment for those diseases.^{6,10}

The impacts of stigma extend beyond patients and clinicians into public policy, research and advocacy. The lung cancer community faces disproportionately low funding for basic research and clinical trials as compared to other cancers based on number of deaths. There appears to be reluctance from celebrities and community leaders to step forward and serve as champions for a stigmatized disease. Additionally, non-profit patient advocacy organizations struggle to build a strong constituent base and recruit volunteers because of the loss, shame and guilt many patients and their loved ones feel.¹⁰

Figure 2: Percent Indicating “Completely Agree” or “Somewhat Agree” With This Statement



“I think part of it is how society views people who smoke and use tobacco. This is something that those people brought on themselves, you know? I did not have to get this, people care about it less.”

Male smoker, Dallas

WHAT WORKS TO REDUCE STIGMA?

If stigma is the product of ignorance, fear, blame and hopelessness, it stands to reason that effective interventions to reduce lung cancer stigma must work to increase knowledge and empathy, and to instill hope.

Knowledge

Experts in health-related stigma as well as the Lung Association’s opinion research respondents concur that knowledge is power when it comes to reducing stigma. Getting the facts about lung cancer demystifies the disease, increases its visibility and gets people talking to one another. A public that understands and appreciates the prevalence and severity of the disease

feels an increased sense of urgency to fight it.

Raising public awareness that lung cancer can strike people who have never smoked and former smokers who quit many years ago challenges negative stereotypes, and shifts blame away from the patient. Someday, the knowledge that smoking is not the only cause of the disease will hopefully eradicate that inevitable question every person living with lung cancer comes to dread — “Did you smoke?”

It is also important to draw public attention to new advances in research and treatment as a way to bring messages of hope to the lung cancer community. When treatment options reduce the mortality rate and increase the number of lung cancer survivors, newly diagnosed lung cancer patients will have a greater feeling of hope.

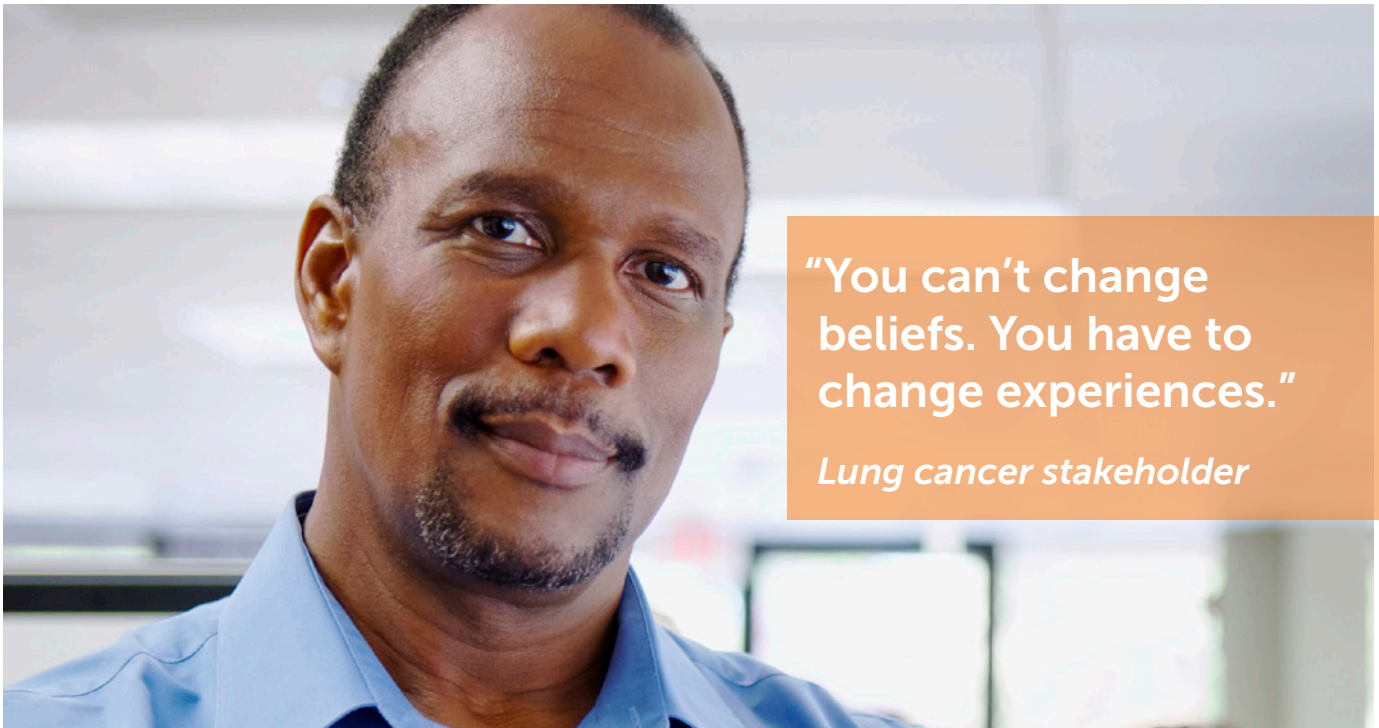
A human face

Every person with lung cancer is someone’s mother, father, son or daughter. When lung cancer patients and their families publicly share their stories and experiences, they help to put a human face on the disease. This gives the general public a reason to care — and to act. It also empowers other people living with lung cancer to speak up and advocate for themselves.

“...doctors need to be more sympathetic with their patients.”

Female lung cancer survivor, Philadelphia





“You can’t change beliefs. You have to change experiences.”

Lung cancer stakeholder

While it is important not to minimize the deadly role that smoking plays in lung cancer as a public health threat, most lung cancer stakeholders agree that highlighting an individual’s smoking history in stories is not effective in reducing stigma and often reinforces blame.¹⁰ People living with lung cancer all face a similar journey, and it shouldn’t matter how they got the disease.

Unity of purpose

There is consensus among stakeholders that patients, advocates, researchers and public health and health-care professionals would benefit from unified messaging about lung cancer. Suggested elements of that messaging include focusing on the fact that anyone can get lung cancer, the need for improved quality of life for those living with lung cancer, and an emphasis on hope and emerging scientific advances.^{1,10}

RECOMMENDATIONS FOR ACTION

Stigma is a complex issue that demands a multifaceted approach. As efforts to reduce the stigma associated with lung cancer move forward, everyone has a role to play. Patients, families, healthcare professionals, researchers and advocates will be more powerful in this initiative if they all combine forces. Some specific recommendations include:

- Funders must support research to better understand the impact of stigma on health care and treatment options, and to monitor and evaluate the success of stigma-reduction efforts.
- Decision-makers and lung cancer advocacy organizations must focus on activities that promote self-efficacy, such as early detection screening and patient empowerment.
- Healthcare professionals must treat people with lung cancer in an empathetic, non-judgmental and supportive way, and link them with support tools.
- Lung cancer advocacy organizations must commit to delivering messages about lung cancer that do not perpetuate stigma.
- Patient advocates must work together in ways that unify the lung cancer community, and not separate people facing lung cancer based on their smoking histories.
- Patients, their families and their community support networks must speak up about lung cancer, and put an end to the era of the “invisible cancer.”

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

Lung cancer stakeholder

GET INVOLVED WITH THE LUNG ASSOCIATION

The American Lung Association has a number of ways people living with lung cancer and their loved ones can get more involved with the lung cancer community. You can:



- Share your lung cancer story on Facing Lung Cancer: Support from Day One (www.mylungcancersupport.org).



- Learn, share and care about lung cancer by joining LUNG FORCE, a movement uniting women to stand against lung cancer and for lung health (www.LUNGFORCE.org).



- Offer your support and guidance to others facing lung cancer on the Lung Connection (www.lung.org/connection).



- Sign up to be an e-advocate at lungaction.org.

REFERENCES

¹Chambers et al. A systematic review of the impact of stigma and nihilism on lung cancer outcomes. *BMC Cancer*. 2012; 12:184.

²van Brakel WH. Measuring health-related stigma – a literature review. *Psychol Health Med*. 2006; 11(3):307-334.

³Chapple A, Ziebland S, McPherson A. Stigma, shame, and blame experienced by patients with lung cancer: qualitative study. *BMJ*. 2004; 1-5.

⁴Conlon A, Gilbert D, Jones B, Aldredge P. Stacked stigma: oncology social worker's perceptions of the lung cancer experience. *J Psychosoc Oncol*. 2010; 28 (1): 98-115.

⁵Wassenaar TR, Eickhoff JC, Jarzemyk DR, Smith SS, Larson ML, Schiller JH. Differences in Primary Care Clinicians' Approach to Non-small Cell Lung Cancer Patients Compared with Breast Cancer. *Journal of Thoracic Oncology*. 2007; 2(8): 722-8.

⁶Hamaan HA, Ostroff JS, Marks EG, Gerber DE, Schiller JH, Craddock Lee SJ. Stigma among patients with lung cancer: a patient-reported measurement model. *Psycho-Oncology*. 2013. 23: 81-92.

⁷U.S. National Institutes of Health. National Cancer Institute: SEER Cancer Statistics Review, 1973-2008

⁸American Lung Association. Research on the Stigma of Lung Cancer: Final Report. 2012.

⁹Cataldo JK, Jahan TM, Pongquan VL. Lung cancer stigma, depression, and quality of life among ever and never smokers. *Eur J Oncol Nurs*. 2012 July ;16(3): 264-269.

¹⁰American Lung Association. Lung Cancer Stigma Stakeholder Research Findings. Dec. 2013.



ABOUT THE AMERICAN LUNG ASSOCIATION

Now in its second century, the American Lung Association is the leading organization working to save lives by improving lung health and preventing lung disease. With your generous support, the American Lung Association is "Fighting for Air" through research, education and advocacy. For more information about the American Lung Association, a holder of the Better Business Bureau Wise Giving Guide Seal, or to support the work it does, call 1 800 LUNG USA (1 800 586 4872) or visit www.lung.org.

Supported in part with funding from Genentech