



Building Support Where There is
None:

The National Lung Cancer Support
Group Network

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BMSF Summit

LUNG CANCER ALLIANCE

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- Saving lives and advancing research by empowering those living with or at risk for lung cancer
- 20 years
- Washington, DC
- Free support, information, and resources



THE HISTORY

- Online group list
- Facilitator's Guide
- Informal support and connection
- Lung Cancer Support Group Facilitator Award



Photo credit: Sam Levitan

THE NEED

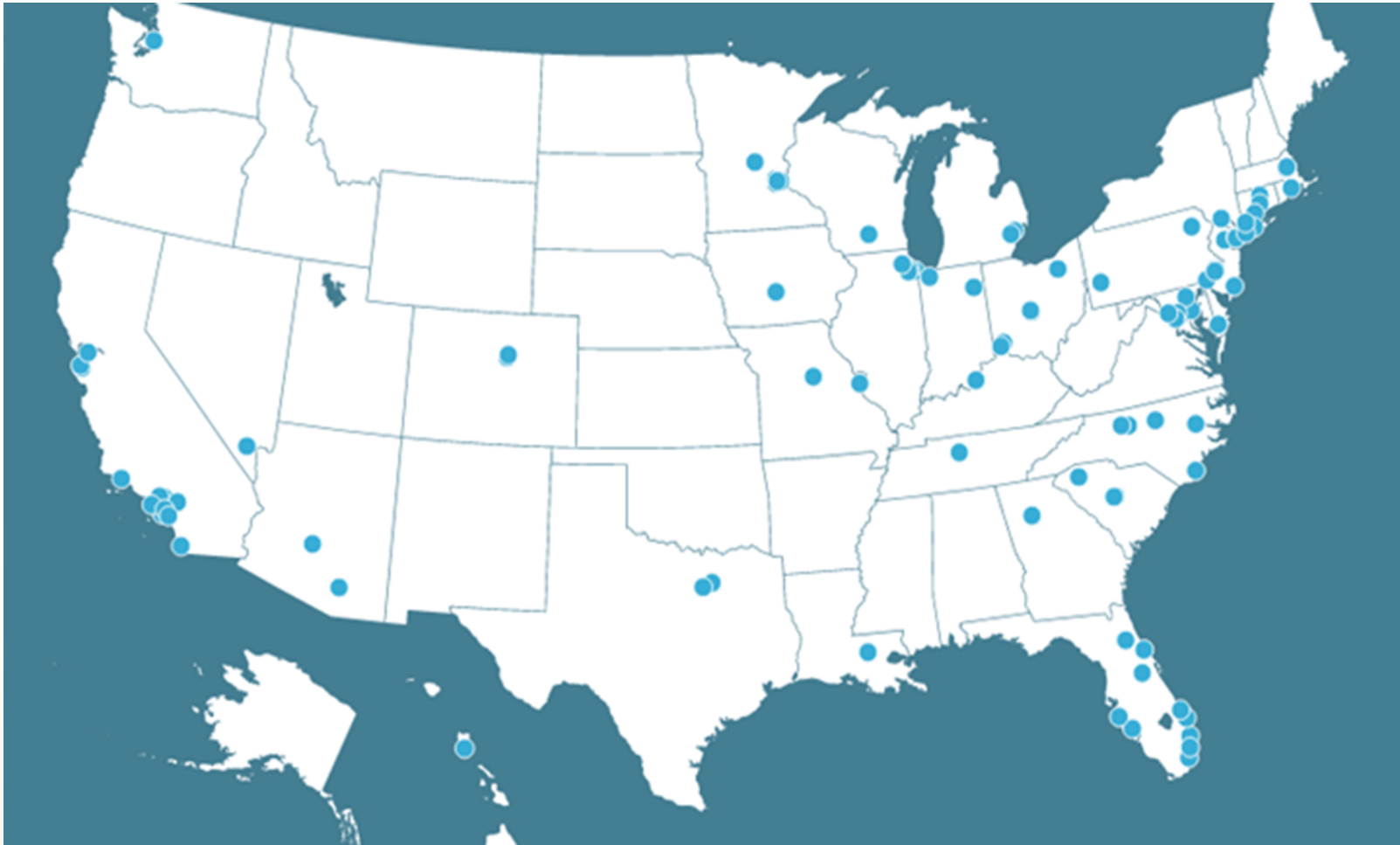
[Lung cancer] patients must be recognized as truly high risk [for distress] and special attention in terms of early detection and intervention is warranted.

Zabora J, BrintzenhofeSzoc K *et al.* The prevalence of psychological distress by cancer site. *Psycho-Oncology* 2001;**10**:19-28.



LUNG CANCER SUPPORT GROUPS

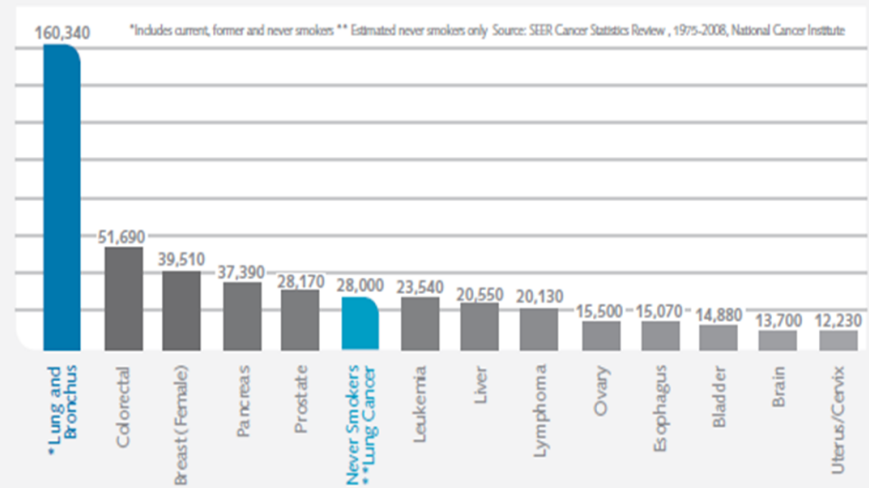
There are fewer than 100 lung support groups in the US



CHALLENGES

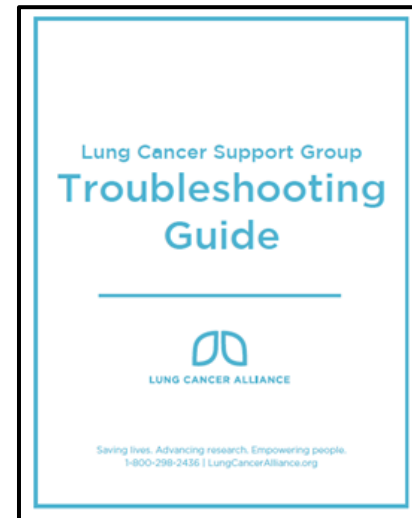
- Stigma with lung cancer
- Misconceptions about support groups
- High mortality rate

LUNG CANCER IS THE LEADING CAUSE OF CANCER DEATH IN EVERY ETHNIC GROUP



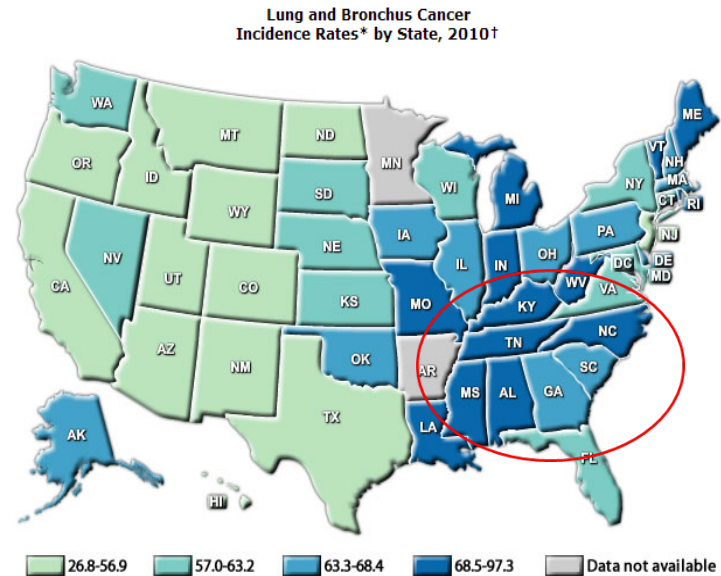
OBJECTIVES OF GRANT

- Create LCA pilot program
- Increase engagement
- Troubleshooting Guide



TARGET POPULATION

- 8 states
- Cancer Support Communities, independent cancer centers, and hospitals
- Locate, outreach, market, assist, and monitor



RESEARCH

- Questionnaires
- Focus Groups

WINDOW MB005

Site #: _____
Participant #: _____

Lung Cancer Support Groups
2015 Support Group: Baseline Questionnaire

Thank you for taking time to complete this survey. Your answers will help us understand how we can better meet the needs of people affected by lung cancer.

Today's date: _____

Section 1: Background/Demographics

1. I am attending as a:
 - a. Person with cancer/Cancer survivor
 - b. Spouse/Partner
 - c. Family member
 - d. Friend
 - e. Other (please specify) _____
2. What is your race/ethnicity? (Check all that apply)

<input type="checkbox"/> American Indian or Alaska Native	<input type="checkbox"/> Native Hawaiian or Other Pacific Islander
<input type="checkbox"/> Asian	<input type="checkbox"/> White
<input type="checkbox"/> Black or African American	<input type="checkbox"/> Other: _____
<input type="checkbox"/> Hispanic or Latino	
3. How old are you? _____
4. What is your gender?
 - a. Female
 - b. Male
5. In general, would you say your health is:
 - a. Excellent
 - b. Very Good
 - c. Good
 - d. Fair
 - e. Poor
6. Stage is how widespread the cancer is at the time of diagnosis. To the best of your knowledge, at what stage of lung cancer were you first diagnosed? If you are a caregiver or loved one caring for someone living with lung cancer, at what stage of lung cancer was he/she first diagnosed? (Please select one)
 - a. Stage 0 (the cancer has not spread beyond the inner lining of the lung)
 - b. Stage I (the cancer is small and has not spread to the lymph nodes)
 - c. Stage II (the cancer has spread to some lymph nodes near the original tumor)
 - d. Stage III (the cancer has spread to nearby tissue or to far away lymph nodes)
 - e. Stage IV (the cancer has spread to other organs of the body, such as the other lung, brain, or liver)
 - f. I don't know
 - g. Other (please specify) _____

Site #: _____
Participant #: _____

Lung Cancer Support Groups
2015 Support Group: Post Attendance Questionnaire

Thank you for taking time to complete this survey. Your answers will help us understand how we can better meet the needs of people affected by lung cancer.

Q. How many times have you attended the support group? _____

Section 1: Self-Efficacy

1. As a result of my participation in this lung cancer support group, I am confident I can ask my healthcare team questions about side-effects of lung cancer and its treatment (such as pain, fatigue, and distress).
 - a. Strongly Disagree
 - b. Disagree
 - c. Neutral
 - d. Agree
 - e. Strongly Agree
2. As a result of my participation in this lung cancer support group, I am confident I can make treatment decisions in partnership with my healthcare team.
 - a. Strongly Disagree
 - b. Disagree
 - c. Neutral
 - d. Agree
 - e. Strongly Agree
3. As a result of my participation in this lung cancer support group, I am confident that I have more information about accessing resources that may be helpful to me.
 - a. Strongly Disagree
 - b. Disagree
 - c. Neutral
 - d. Agree
 - e. Strongly Agree
4. I would recommend this lung cancer support group to others with lung cancer and their loved ones.
 - a. Strongly Disagree
 - b. Disagree
 - c. Neutral
 - d. Agree
 - e. Strongly Agree
5. General comments or suggestions about this lung cancer support group: _____

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CURRENT STATUS

- Currently Running:
 - Gilda's Club-Nashville, TN
 - Cornucopia-Durham, NC
- West Virginia University Hospital
 - August 2015
 - November 2015 visit
 - IRB approval pending



CURRENT STATUS

- Pending:
 - Medical University of South Carolina-Charleston, SC
 - Greenville Healthcare-Greenville, SC
 - Kirkland Cancer Center-Johnson City, TN
 - Northeast Georgia Health Center-Gainesville, GA



CHALLENGES

- Communication
- Hospital politics
- Understaffed areas
- Research



KEY NEXT STEPS

- Website change
- Newsletter to facilitators
- Weekly Breather
- Continued outreach to treatment centers



WILDCARD

- Jenny White
- Desire for a support group
- Advocate/volunteer
- Motivator





THANK YOU!

LUNG CANCER ALLIANCE