

SUPPORT GROUPS FOR PEOPLE WITH LUNG CANCER: THE ROLE OF THE NON-PROFIT ORGANIZATION

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BACKGROUND

The need for psychosocial services is great in the lung cancer community. An estimated 220,000 people will be diagnosed this year and research indicates people with lung cancer experience high levels of distress and have greater unmet physical and emotional needs than those with other types of cancer. A significant unmet need for people with lung cancer is social support.

In-person support groups are valuable for people affected by lung cancer because they offer the chance to connect with others who understand. Benefits of groups including increased feelings of control and confidence and decrease in depression and distress.

Most people with the disease prefer lung cancer-specific support groups, however such groups can be especially challenging to start and maintain. As a result, there are **fewer than 100 lung cancer specific groups active in the United States**.

LUNG CANCER ALLIANCE

The efforts of national cancer organizations to ensure those diagnosed and their loved ones have the information and psychosocial support they need aid, complement and reinforce programs offered at cancer treatment and support centers.

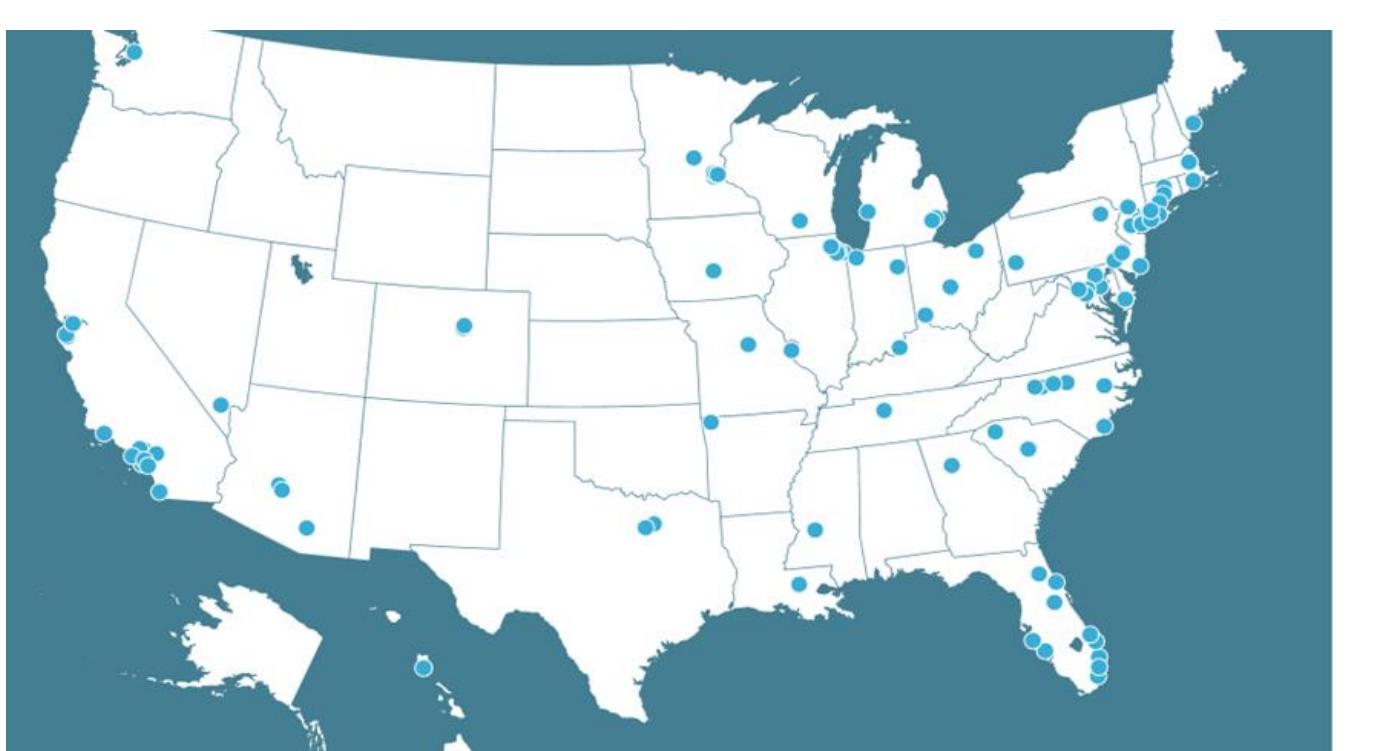
As a patient advocacy and support organization, a key part of Lung Cancer Alliance's mission is to understand and help address the psychosocial needs of people with lung cancer and their loved ones.

Lung Cancer Alliance has employed several innovative ways to help existing support groups thrive and foster new ones.

SUPPORT GROUP TRACKING

For nearly 20 years we have maintained a centralized list of lung cancer support groups in the US on our website.

We also keep in touch with facilitators and offer our expertise and assistance to those in need.



Lung cancer support groups in the United States

FACILITATOR AWARD

Through contact with lung cancer group facilitators, we have gained a deeper understanding of the challenges in starting and maintaining lung cancer groups, as well as the creative ways successful facilitators have overcome those challenges.

Since 2009, we have recognized uncommon dedication through the annual Lung Cancer Support Group Facilitator Award.



Win Boerkel LCSW
Cancer Care 2009

Sue Abbinanti
Alexian Brothers
2010

Irene Scanlon & Linda David
Stony Brook 2011

FACILITATOR SURVEY

To learn more, in 2013 we partnered with two other organizations to conduct a survey of lung cancer group facilitators in the United States (US), the United Kingdom (UK) and Australia (AUS).



Key Findings

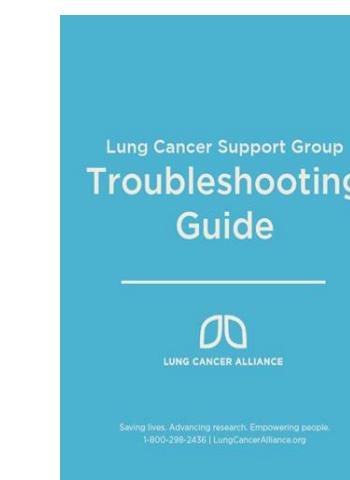
- 74 responses (56% response rate)
- 75% in AUS/UK and 71% in US said their groups were successful
- Most groups were:
 - Once a month
 - Comprised of both survivors and loved ones
 - Professionally led (more the case in the US)
 - Co-facilitated
 - Both education and support

Groups in AUS are most often held in cancer centers. Many in the UK are as well but in the US groups are equally as likely to be in a center that only provides support for people with cancer.

Groups in the US tend to have fewer participants per group. Three groups in the US are led by lung cancer survivors compared to none in the UK and AUS.

TROUBLESHOOTING GUIDE

The results of the survey, along with an extensive literature review, became the Lung Cancer Support Group Troubleshooting Guide, full of tried and true ways struggling groups can become successful.



SUPPORT GROUP PILOTS

The National Lung Cancer Support Group Network was launched with the initiation of two support group pilots, both within an area of high need with little support: the Tobacco Belt.



Professionally Led Groups

The pilot allows us to sponsor and co-brand three new lung cancer support groups, one at a Cancer Support Community affiliated center, one in a hospital setting and the third at an independent cancer support facility.

The first launched at Merit Health Center in Jackson MS in March, the second at Gilda's Club Nashville in April and we are in the planning stages of sponsoring a group in an independent support center in North Carolina.

The three groups in this pilot are professionally led, take place twice a month and include a research component to more fully help us understand the successes and challenges around starting new groups.

Peer Led Groups

Peer led cancer support groups are controversial in many professional circles. However, research shows that such groups can be successful. And in some areas, lack of resources is an impediment to professionally led groups.

Building on lessons learned from other organizations, the second pilot allows us to test three methods of identifying engaging and training appropriate lung cancer survivors interested in starting groups. These groups will be based on a successful model in use by a survivor facilitator which involves monthly meetings attended by a healthcare professional such as a patient navigator, not as facilitator but as a resource and go-to person for group members who have questions about lung cancer or need clarification on their treatment and options.

At completion of the pilots, six additional lung cancer groups will be available in areas of high need, as we continue to work to improve the viability of struggling groups through distribution of the Troubleshooting Guide and connecting those facilitators with successful ones for information and assistance.

ADDITIONAL PROGRAM ELEMENTS

Dedicated Staff

In 2014, we hired a social worker, Kate Abramson, who spends more than half her time managing our support group pilots and initiatives, and in maintaining relationships with existing facilitators.

Pending funding, Kate plans to start a lung cancer group in Washington DC where no successful groups currently exist.

Tiered Approach

We have developed a four-tiered structure of helping lung cancer support groups, from the basic level of listing the group on our website and supplying the group our educational materials to full sponsorship of new groups within areas of high need with a lack of support. For all groups we provide technical assistance and connection with successful facilitators for tips and support.

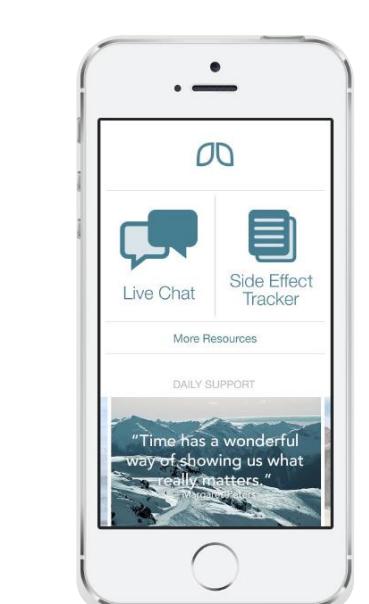
Filling the Gaps

Even if lung cancer support groups were available in all parts of the country, some people who seek support would not attend. It can be hard to get to an in-person group, physically or emotionally. Sometimes a person can't find someone with whom they can relate at a local group.

To fill gaps in support, we offer two unique ways for people to connect.



The **Phone Buddy Program** connects survivor volunteers with people going through or out of treatment by telephone for information, hope and support.



LCA Unite app for Android and iPhone - in addition to providing a platform for tracking treatment side effects and locating events, Screening Centers of Excellence and clinical trials, LCA Unite offers a chat feature and the ability to easily locate local lung cancer groups.

CONCLUSION

Through a thoughtful and integrated approach, Lung Cancer Alliance is helping the lung cancer community access vital psychosocial support. We offer support groups expertise on improving groups and through the research component of the pilots, we are measuring the impact of the groups and the replicability of the model.

Importantly, we are learning valuable information and best practices as well as adding to the limited body of knowledge on starting and maintaining successful lung cancer support groups.

RESEARCH IMPLICATIONS

Through collaboration with the Cancer Support Community's Research and Training Institute, the professionally-led group pilot includes a research component to measure the impact on attendees through pre and post questionnaires, follow up forms and focus groups. This research will add to the body of knowledge on the effectiveness of lung cancer-specific support groups, which is lacking.

We will also conduct focus groups with the peer-led groups and will be able to compare them against the professionally led groups as well,

We hope our efforts will lead researchers to use our groups and our knowledge to study the all-important questions around what makes a successful lung cancer group and how non-profit organizations can assist in helping them to thrive.

PRACTICE IMPLICATIONS

Psychosocial professionals can view national advocacy organizations and the services provided as partners. Our goal is not to replace but to enhance services offered in cancer centers and the community and to foster them where lacking.

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