



# 2017 LUNG CANCER ALLIANCE IMPACT REPORT

[www.lungcanceralliance.org](http://www.lungcanceralliance.org)

1-800-298-2436



## 2017 LUNG CANCER ALLIANCE IMPACT REPORT



Thank you! On behalf of the entire Lung Cancer Alliance staff and Board of Directors, we extend our gratitude to the broader lung cancer community. Because of your support—whether you donated, volunteered or told a friend in need about our services—Lung Cancer Alliance helped thousands of people impacted by lung cancer in 2017.

Our trained support staff provided emotional and educational support through our HelpLine, support group network, peer-to-peer counseling programs, “Coping with Treatment Side Effects” webinar series and treatment navigation resources. We hosted the 9th National Advocacy Summit with double the number of survivors we had in past years. Our signature Shine a Light on Lung Cancer events and our national Lung Love Run/Walks gathered more than 3,000 community members to celebrate, remember and connect.

Lung Cancer Alliance welcomed over **600,000** visits to our website and distributed over **119,000** print and digital publications. Through our robust social media channels, reaching over **17,000,000** people and media presence with **500,000,000** impressions, we were able to raise awareness around the disease and connect more of our community than ever before.

Supporting our important work were individual contributions, foundation grants and sponsorships from individuals and organizations that share our lifesaving mission. Together the lung cancer community’s engagement and financial support inspires us to develop and deliver the services most needed by the community touched by lung cancer.

In this Annual Report, you will learn more about the programs and services we provided in Fiscal Year 2017. You will also read about our enhanced website, as well as our growing networks of people, resources and programs. We always remember that these are your successes too.


On behalf of the people we serve, thank you for your support and dedication to our mission.

Sincerely,

**Laurie Fenton Ambrose**  
Lung Cancer Alliance, President and CEO





A young man and woman are walking together outdoors. The woman, in the foreground, is wearing a teal t-shirt with a white logo, a black baseball cap, and glasses. She is smiling and looking towards the man. The man is also wearing a teal t-shirt with the same logo and has his arm around her shoulder. They are both holding water bottles. The background is a blurred outdoor setting with trees and other people.

*“I have served the lung cancer community for the past 12 years, but it all started for me when my mom, a two-time survivor and lung warrior, was diagnosed with the disease. Your support allows us to serve people like my mom by helping advance cutting edge research that is shifting lung cancer from a fatal to manageable and even curable disease, ensuring access to quality treatment and care, and providing free personalized one-on-one support, information and referrals via our experienced support staff team. Each day I come to work ready to do everything in my power to fight lung cancer on behalf of my mom and all those touched by the disease.”*

**Emily Eyres,**  
Chief Operating Officer, Lung Cancer Alliance

A group of people are walking on a paved path outdoors. Many of them are wearing teal t-shirts with the Lung Cancer Alliance logo. Several people have their arms raised in the air, suggesting a celebratory or supportive gesture. The background shows trees and a clear sky.

## OUR MISSION

Lung Cancer Alliance is dedicated to saving lives and advancing research by empowering those living with and at risk for lung cancer.

## WHO WE ARE

Lung Cancer Alliance serves and listens to those living with and at risk for lung cancer to reduce stigma, improve quality of life and increase survival. We empower a vibrant and caring community by helping people navigate the paths of early detection, diagnosis, treatment and long-term survival. Insights into our community allow us to improve care, amplify awareness, drive advocacy and lead transformative research.

## WHAT WE DO

Using a science-based, strategic approach, our vision is to triple the number of survivors over the next decade. Reaching this goal requires a collaborative approach that includes:

- Providing Patient Support
- Raising Awareness & Engagement
- Shaping Health Policy
- Accelerating Science & Research
- Improving Access to Care





*“Lung Cancer Alliance sent me diverse information on clinical trials in Germany and Europe. The information reached us at a time when God’s guidance already paved the way for our loved one. However, I do not want to miss sharing how grateful I felt for the information provided to us. I was deeply overwhelmed about the help that reached us despite the geographic distance. It is a proof of how powerful the bond of humanity can be, irrespective of nationality and distance and so much more. The help also touched me personally and sets an example of kind values that needs to be cherished more around this world.”*

Florence, Caregiver



PATIENT SUPPORT

Our support services continue to help those impacted by lung cancer all over the country. These programs, all provided free of charge, offer guidance for those touched by lung cancer at every stage of the process.

**HELPLINE:** Our toll-free line is answered by caring professionals who provide information, support and referral for anyone with questions about lung cancer. This year, we upgraded call center software adding a website tool for visitors to submit questions directly from the website.

**6,500**  
unique website visitors

**More than 2,200**  
unique HelpLine calls and emails from across 48 states

**EDUCATIONAL MATERIALS:** We are dedicated to providing those facing lung cancer with downloadable materials with the most up-to-date and reader-friendly information to improve outcomes. This year we launched our online materials store to make it easier for healthcare facilities to order print materials.

- Immunotherapy
- Targeted Therapy
- Clinical Trials
- Types of Lung Cancer
- Biopsies & Pathology Reports
- Molecular Testing
- Palliative Care
- Lung Cancer Screening
- And more!

**REACH**  
**3,823**  
unique website visitors

**63,702**  
individual print materials distributed to patients at cancer centers representing 42 states



**LUNGMATCH—MOLECULAR TESTING AND CLINICAL TRIALS MATCHING SERVICE:**

Our LungMATCH program is a personalized service that informs and guides patients through the many medical and clinical trial choices, helping them identify the appropriate treatment options to discuss with their doctor.

- **100 patients** referred into the molecular testing program (71% who received a report had an actionable finding)
- **1,400 unique people** completed an online clinical trials search
- **56 patients** received one-on-one trial navigation by phone/email (75% of patients who discuss trials with our navigators go on to discuss clinical trials with their providers)

**REACH** **3,128** unique website visitors  
**100,000** social media reach

**EMOTIONAL SUPPORT:** Our peer-to-peer support programs for lung cancer patients and caregivers, Phone Buddy and GUIDES, remind those going through a difficult time that they are not alone. Phone Buddy and GUIDE volunteers have been through the lung cancer journey or have helped a loved one through it and are uniquely qualified to lend support and share information and resources.

**WEBINAR SERIES “COPING WITH TREATMENT SIDE EFFECTS”:**

Lung Cancer Alliance’s quarterly webinar series on managing side effects from treatment featuring leading experts and patient perspectives included topics like: shortness of breath, digestive problems, anxiety and fatigue.

**REACH** **650** viewers on YouTube

**SUPPORT GROUP NETWORK:** Research shows that the benefits of patients and caregivers attending in-person support groups include increased feelings of assistance, encouragement, control and confidence with a decrease in depression and distress. All of this may lead to improved survival and quality of life. Our National Lung Cancer Support Group Network consists of **more than 90 select lung cancer support groups** across the country.

We are growing this network by providing important resources to prospective facilitators hoping to start a group in their local community, including a “Troubleshooting Guide,” workshops and promotional materials.



*“I decided to become a Phone Buddy volunteer because I lean towards helping others. I found reaching out to others helps me to feel engaged and helpful. I like being helpful and if my story gives other people hope and helpful information I’ve done my service well. Through our shared experiences we uplift each other and I wish the best to all my past, present and future Phone Buddies.”*

**Carly Brady**

Carly volunteers her time as a Phone Buddy. She was diagnosed in December 2011 making her a six and a half year stage 4 lung cancer survivor. She also loves playing her guitar, practicing yoga, painting and spending time with her cat.





*“Attending my first Lung Cancer Summit in 2014 changed my relationship with lung cancer. It empowered me to become a somewhat militant lung cancer advocate and I haven’t looked back. My husband and I have returned each year standing united with an amazing lung cancer community to educate, share our stories and put a face to lung cancer on Capitol Hill. Working TOGETHER to save lives, it doesn’t get any better than that!”*

**Deena Cook**, lung cancer survivor and recipient of the Michael G. Oxley Award



ADVOCACY

Advocacy is about standing up, being visible and being heard. It’s about promoting change and not accepting the status quo. It’s about taking a public stand for those causes and issues that matter most. In 2017, our army of advocates were louder and more powerful than ever before in their efforts to raise awareness and educate the public and policymakers about lung cancer.

Lung Cancer Alliance’s efforts ensured the reestablishment of the Lung Cancer Caucus, a clearinghouse of information to aid Members of Congress in their understanding of the issues surrounding those living with and at risk for lung cancer. Additionally, over the course of the year, **a record-breaking 1,595 messages were sent to policymakers** on issues like cancer research funding and access to care.

Our efforts on Capitol Hill, which would have not been possible without the ongoing dedication of passionate lung cancer advocates, **secured an additional \$14 million in lung cancer research funding bringing the current total funding to \$127.5 million (FY09-FY18)** via the dedicated Lung Cancer Research Program within the Congressional Directed Medical Research Program administered by the Department of Defense (DOD), making it the largest lung cancer research program – public or private – outside of the National Cancer Institute.

REACH

4,064  
unique website visitors

100,000

social media reach

**NATIONAL ADVOCACY SUMMIT:** Our signature advocacy event, the National Advocacy Summit, took place in Washington, DC from September 27-28. More than 100 lung cancer advocates, with almost HALF of them lung cancer survivors, united to share their personal stories with our nation’s leaders and ignite change for all those touched by the disease.

REACH

100 attendees  
(49 survivors)  
from 27 states

140+

congressional meetings

100

messages sent to Congressional Representatives during Lung Cancer Advocacy Action Week

**CONGRESSIONAL BRIEFING SERIES—“THE STATE OF LUNG CANCER”:** The Congressional Briefing Series educates Members of Congress and Congressional staff on issues related to lung cancer. In 2017, Lung Cancer Alliance hosted “The State of Lung Cancer” briefing that delivered on a core advocacy priority – bringing early attention and focus to the needs of the lung cancer community.

More than 80 government leaders and staff, cancer experts and lung cancer advocates came together at the briefing to learn more about advancements and breakthroughs in lung cancer research and treatment and the need for responsible policies and enhanced federal research funding. Lung Cancer Alliance led an expert panel discussion featuring Bill Mayfield, M.D., WellStar Health Systems, a member of Lung Cancer Alliance’s Medical and Professional Advisory Board; and Julie Renee Brahmer, M.D., Interim Director, Sidney Kimmel Comprehensive Cancer Center (Johns Hopkins Bayview campus) & Associate Professor of Oncology.

REACH

80 attendees

40,000

social media reach





## INFORMATION AND EDUCATION

Raising awareness for lung cancer is more critical today than ever before. Unfortunately, lung cancer stigma is still present in our culture, making it essential for those impacted to share their stories, put a face to lung cancer and educate our communities.

We use all available methods to raise awareness for the disease. From sharing fact graphics on social media to telling one's unique story in their local newspaper, every effort helps bring us one step closer to a world where lung cancer, the number one cancer killer, receives the attention and research that will make a difference.

**PUBLIC RELATIONS:** Lung Cancer Alliance is constantly working with national and local media sources to feature lung cancer stories, research and resources. This year we secured **500,000,000 impressions**, reaching more people than ever before.

**SOCIAL MEDIA:** Facebook, Twitter, Instagram – these are all important vehicles to connect our community and share our collective story that breaks down barriers and allows people who have gone through similar experiences to connect and find hope. Our social media channels reached over **17,000,000 individuals!**

**WEEKLY E-NEWSLETTER:** The *Weekly Breather*, an e-newsletter sent to our extensive community, features lung cancer news, research, events, survivor stories and more! Each week, the *Weekly Breather* reaches nearly **40,000 people**.

### EVENTS

#### Shine a Light on Lung Cancer

The largest coordinated lung cancer awareness event in the U.S., consisting of educational events at healthcare facilities (Shine a Light) and fundraisers hosted by individuals (Shine a Light Your Way).

- **Shine a Light:** 167 events across 36 states
- **Shine a Light Your Way:** 55 events

**REACH**

**1,000,000**  
social media reach

**55,000,000**

PR impressions (103 stories, 49 print and 54 broadcast)

**5,846**

unique website visitors

#### Lung Love Run/Walks

Family-friendly 5K run/walk events that bring people together to raise awareness and funds for the fight against lung cancer.

- **Philadelphia, PA:** Philadelphia Zoo, April 22, 2017
- **Portland, OR:** Laurelhurst Park, June 24, 2017
- **Houston, TX:** Buffalo Bayou, November 4, 2017

**REACH**

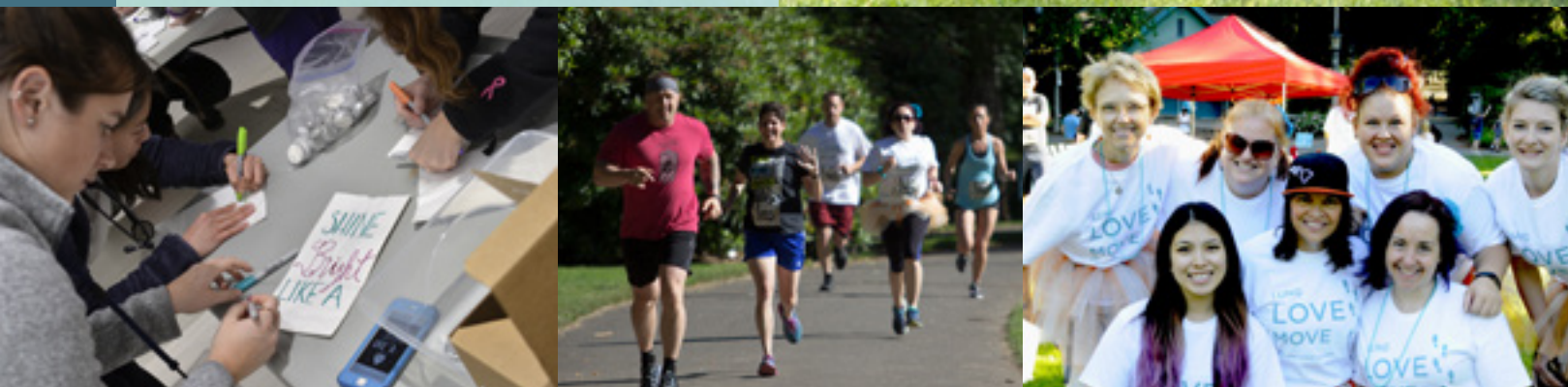
**4,500**  
total miles walked

**1,675**  
participants

**\$116,931** funds raised

*"In August, 2014 I was diagnosed with Stage IV NSCLC. I have attended and helped plan Portland's Lung Love Run/Walk since its inaugural event in June of 2015. Gathering our local lung cancer community has made a big difference in my life and along my cancer journey. I have made life-long invaluable friends and have gained support systems through this event. Thanks to Lung Cancer Alliance, several in our community and the greater Portland area are much more aware of lung cancer. I look forward to many more years of this great event!"*

**Dawn Horner**, Lung cancer survivor and Lung Love Run/Walk Portland planning committee member; diagnosed 8/10/2014 with stage IV NSCLC Adeno. EGFR Exon 20 mutation.



*"Partnering with Lung Cancer Alliance to bring Shine a Light events to the community has been a wonderful experience. They make it easy to host an event, with online registration and all of the materials that are sent, including flashlights! Our annual event just keeps growing, which is so important here in Brooklyn, NY. We have the largest population of older adults in NYC in our borough, along with a high concentration of immigrants; both shown to be current or former smoking populations and are therefore at high risk of developing lung cancer. We continually recruit first time screeners at this event, which just proves that an ongoing message is just as important as the first one. Thank you to LCA for bringing this amazing program to us!"*

**Jody Ruth Steinhardt, MPH, CHES®** Coordinator, Lung Cancer Screening Program Maimonides Medical Center





## DETECTION AND TREATMENT

We guide the at-risk and patient community to our Screening Centers of Excellence and treatment center networks and share best practices, patient education tools and research opportunities with healthcare professionals.

**SCREENING CENTERS OF EXCELLENCE (SCOE) NETWORK:** Our network of Screening Centers of Excellence are committed to responsible, high-quality screening within a continuum of care. The designation of SCOE aims to ensure responsible screening is carried out safely, efficiently and equitably. At the end of 2017, there were more than **530 centers** nationwide and it continues to grow.

This year, we created an online application process and launched the Screening Excellence Exchange to create direct peer-to-peer connections and networking. Additionally, we initiated network-wide data collection, presented data in various forums with publication anticipated in 2018.

**SCREENING AND CARE CONFERENCE :** The annual conference takes place each fall in Washington, DC, bringing together healthcare professionals from lung cancer screening and care programs across the country to meet, share lessons learned, troubleshoot problems and identify continued areas of need.

**31** states represented **140** professional attendees (42% repeat attendees)

*"We initiated our Lung Cancer Alliance Screening Center of Excellence in February of 2016, as soon as coverage benefits became available. We have worked hard to develop and grow our program since. The Lung Cancer Alliance Screening and Care Conference has been a crucial element to our success. It provided us with a standard of care goal that we strive to meet and exceed with every patient we screen. The conference provides us with an opportunity to network with colleagues who are walking the same path and experiencing the same barriers to care, yet often times arriving at solutions before us. The Screening and Care Conference allows us to share efforts, insights and knowledge to overcome obstacles to successful screening. Through this sharing, we will succeed."*

**Sarah F. Groce, RN, MSN, AGACNP-BC,**  
Cone Health | LeBauer Pulmonary  
Critical Care Medicine  
Nurse Practitioner, CHMG | Cone Health Lung  
Cancer Screening Program, Nurse Navigator



*"Each and every day we are making a difference in someone's life by connecting lung cancer patients with our support staff, through our free HelpLine, bridging the gap between cancer researchers in the lab and lung cancer survivors in the real world and ensuring those at risk for the disease know about and have access to high-quality, preventive services like lung cancer screening."*

**Jennifer King, PhD,**  
Director of Science & Research at  
Lung Cancer Alliance

## RESEARCH

We advance scientific discovery by contributing patient perspectives and insights about new treatments, collaborating on innovative studies with leading academic institutions and connecting patients to clinical trials and research projects.

### SCIENTIFIC PAPERS/PRESENTATIONS:

The Lung Cancer Alliance team presented our life-saving science and research programs at the 19th International Psycho-Oncology Society World Congress in August and the 18th IASLC World Conference on Lung Cancer in October. We published **two scientific papers** on decreasing lung cancer mortality through screening and lung cancer stigma.

**9** posters presented at scientific meetings **6** oral presentations

### LungMATCH:

LungMATCH is a free comprehensive program to help patients find and understand the personalized treatment options that are right for them. The program focuses on two key areas of treatment: molecular testing and clinical trial matching. In the first full year since the program launched in late 2016, we increased our clinical trial matching 10-fold each month!

Assisted over  
**1,000**  
people with help  
finding a clinical trial

**100**  
patients enrolled  
in the Molecular  
Testing program

*"I support LCA as a LungSAVER monthly donor and through other fundraising events as a way for me to create awareness, which saves lives. I never thought my family would be impacted by the disease and I want to ensure that everyone understands their risk and the statistics of the disease – and LCA is doing that outreach and education in communities across this country."*

**Mike Suskin,** Lung Cancer Alliance donor

### YOUNG INVESTIGATOR AWARD:

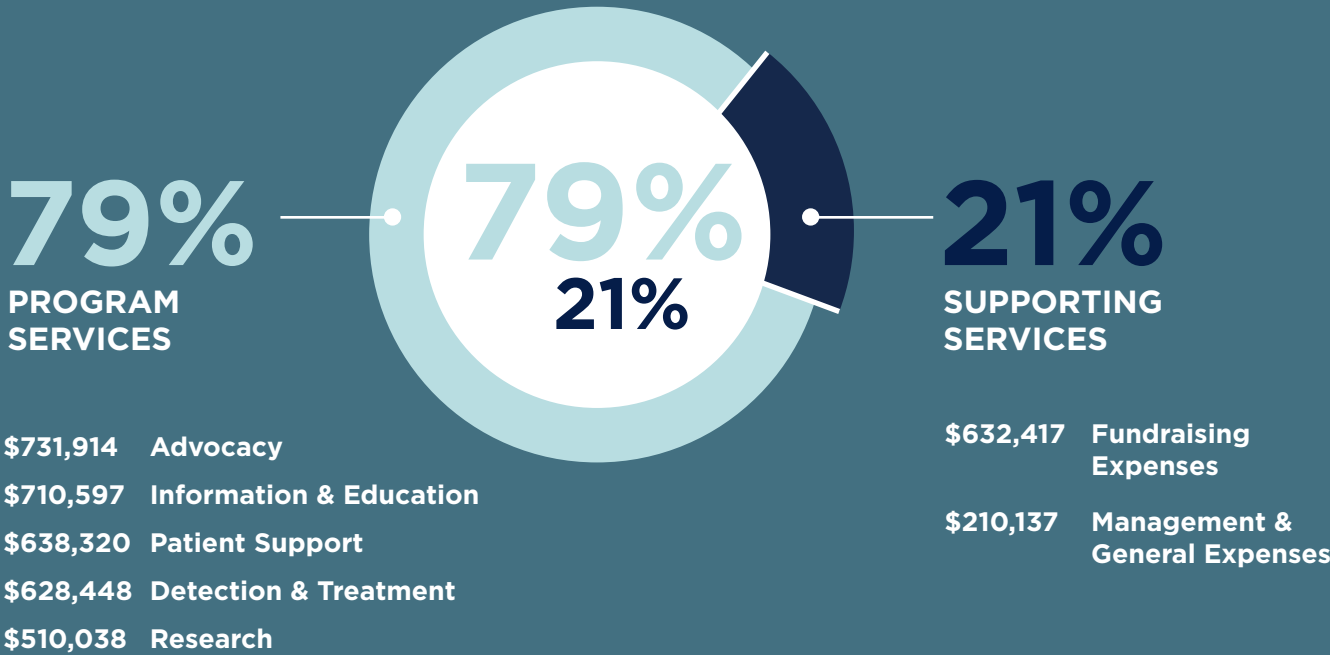


In partnership with the Conquer Cancer Foundation of the American Society of Clinical Oncology (ASCO) Young Investigator Award program, we fund promising young researchers in the field of lung cancer. Through this grant we encourage the best and brightest to choose lung cancer as their field of study.

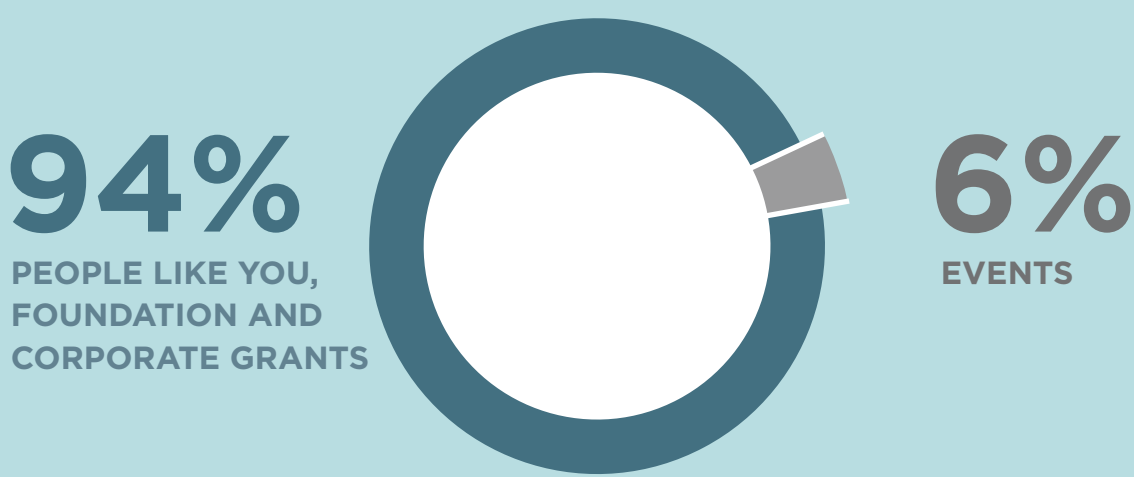
Our 2017 Young Investigator was Robert Smyth, MB, MSc of the Royal College of Surgeons in Ireland. His research examines whether mutations in tumors can be identified through a patient's breath – providing a non-invasive, inexpensive and a more-accessible option to help identify the best treatments for lung cancer. The findings will provide people across the world with more information about their cancer and thus better treatment options.



HOW WE SPEND MONEY



WHERE THE MONEY COMES FROM



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Lung Cancer Alliance's Board of Directors is composed of volunteer leaders committed to helping the organization raise awareness for lung cancer, lower stigma and increase survivorship. We are incredibly grateful for their thoughtful and guiding service to this community.

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\*Member of the Board of Directors      \*\*Member of the Honorary Board of Directors      † Deceased



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We are so grateful to receive support from a variety of corporations, businesses, affinity groups and more. Recognized below are the following organizations whose generosity exceeded \$500 in 2017.

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**LUNG CANCER  
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