Lung Cancer Alliance

GuideStar Nonprofit Profile Charting Impact Report * Last Updated on 10.05.2017

This report represents Lung Cancer Alliance's responses to Charting Impact, a joint project of BBB Wise Giving Alliance, GuideStar USA Inc, and Independent Sector. Charting Impact uses five simple yet powerful questions to encourage strategic thinking and help organizations share concise information about their plans and progress toward impact.

Lung Cancer Alliance
1700 K Street, N.W. Suite 660, Washington, DC 20006
202-463-2080 (ext. 1424)
http://www.lungcanceralliance.org

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

The content of this Charting Impact Report is the sole product and responsibility of Lung Cancer Alliance. This report does not in any way represent an endorsement from Independent Sector, BBB Wise Giving Alliance, or GuideStar, nor does it represent fulfillment of the BBB Wise Giving Alliance’s Standards for Charity Accountability. For more information on Charting Impact, visit www.guidestar.org/chartingimpact
1. What are we aiming to accomplish?

Lung Cancer Alliance is dedicated to saving lives and advancing research by empowering those living with and at risk for lung cancer—the leading cause of cancer death in the US and worldwide. Our work is critical as lung cancer represents almost 1/3 of all cancer diagnoses today losing more people each year than breast, prostate, and colon cancers combined. In 2015, more than 220,000 people will be diagnosed and 157,499 will not survive. About 85% of newly diagnosed patients will not live longer than five years making lung cancer one of the most lethal cancers. Over 75% are diagnosed at late stage and are not curable. As a result, lung cancer’s survival rate is only 19% whereas breast, prostate and colon cancer survival rates are 89%, 99% and 65% respectively. Lung cancer patients are also routinely blamed and thus stigmatized for their disease even though 80% of those diagnosed do not smoke (60% are former smokers, 20% are never smokers). The number of new cases is expected to increase by 52% over the next 20 years. By 2020 the value of lives lost to lung cancer will be $440 billion - three times higher than any other cancer. A 4% annual decrease in mortality rates would cut that cost in half. Lung Cancer Alliance depends entirely upon the generosity of our donors to advance our mission. We serve the multiple millions of Americans touched by and at risk for the disease with a focus on underserved communities and special populations who are disproportionately impacted. For example, we help Veterans to understand their higher risks for lung cancer and empower them to take action with free on-line risk assessments and where to go to be screened responsibly. We help women understand that lung cancer is their leading cause of cancer death – nearly 200 women per day – spreading awareness and providing resources to help them and their families make informed decisions. And we are dedicated to fighting for lung cancer screening and treatment programs that saves lives and advances the research that brings us closer to the cures. Using a science-based, strategic approach, we aim to triple the number of survivors over the next decade. Reaching this impact goal requires a collaborative approach that includes: advocating for continued increases in research funding; conducting awareness campaigns on the disease, risk and early detection; providing free psychosocial support, information, navigation and referral services; delivering best-practice, high-quality programs to ensure responsible screening and treatment excellence; and pursuing comprehensive public health policies for the disease - from prevention and wellness to early detection and treatment – at the national, state and local levels.

2. What are our strategies for making this happen?

PROVIDING SUPPORT: We ensure our community has current, credible information and the emotional support to make informed decisions to extend survival. RAISING AWARENESS & ENGAGEMENT: We ignite national dialogue about the disease to educate the American public, eliminate stigma and inspire action by a growing and compassionate community for change. SHAPING HEALTH POLICY: We lead national advocacy efforts by educating policymakers and government agencies to our community's priority needs: increasing research funding, expediting new treatment approvals and improving access to high quality, affordable healthcare. ENHANCING SCIENCE & 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. IMPROVING ACCESS TO CARE: 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.

3. What are our organization's capabilities for doing this?

Lung Cancer Alliance is one of the highest rated nonprofit organizations dedicated to fighting lung cancer in the nation. Since 1995, Lung Cancer Alliance has played a critical role in every major advance – changing how we talk about, detect and treat the disease – and turning patients into survivors. From our beginnings to our role today as the national leader supporting our community, we have made significant progress in fighting this deadly disease. Starting as a 2-person nonprofit with lung cancer rarely mentioned or discussed, and routinely blamed on the patient, we have elevated this disease to a national level deserving compassion, care, and support no different than any other. These milestones include: · Securing historic
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legislation signed into law – the Recalcitrant Cancer Research Act – requiring the National Cancer Institute to develop a strategic plan on how to fight lung cancer. · Establishing the first-ever federal research funding pipeline for the disease with more than $113 million secured to date – the largest lung cancer research program outside of the National Cancer Institute. · Leading the 10-year effort that successfully secured lung cancer screening as a fully covered preventive service under the Affordable Care Act and Medicare/Medicaid for the millions at high risk for the disease. · Leading the responsible implementation of lung cancer screening with our award winning National Framework for Excellence in Lung Cancer Screening & Continuum of Care with a growing network of more than 500 Lung Cancer Alliance Screening Centers of Excellence nationwide. · Delivering the first-ever 1-800 Lung Cancer HelpLine, LC support app, and LungMATCH treatment navigation and molecular profiling, support and referral programs provided free of charge to thousands of families every year. · Igniting first-ever, positive national dialogue about the disease through award winning education campaigns, starting with the landmark No One Deserves to Die campaign reaching more than 100 million people. · Establishing the National Lung Cancer Support Group Network as the only resource for developing in-person lung cancer support groups providing training and educational materials in areas of high need. · Developing and distributing the leading educational resource series on Understanding Lung Cancer to network of more than 1200 healthcare providers serving patients and their families at over 700 medical facilities nationwide.

4. How will we know if we're making progress?

Progress toward the impact goal of tripling the number of survivors over the next decade is how we hold ourselves accountable to our mission. Our national board of directors quarterly reviews benchmarks and annually monitors progress of survival rates, research funding levels, diagnosis and treatment breakthroughs, stigma reduction and federal response. We are also incorporating additional measurement tools to more precisely gauge our impact and improve upon psychosocial support services, educational materials, partner technical assistance and outreach to higher risk audiences such as Veterans and minorities. In the short term, we track our progress through scientific research we are able to advocate and secure funding for, the number of public health policies enacted, the number of people we serve, the number of medical facilities in our excellence programs, the number/impact of publications, the number of attendees and presentations at professional meetings, the number of people participating in educational awareness and support programs, media impressions for our awareness campaigns, news releases, website visits and social media reach.

5. What have and haven't we accomplished so far?

Lung Cancer Alliance initiated and continues leading the movement in the fight against lung cancer. What we accomplished in less than eight years took other disease movement's decades. We led the historic passage of legislation prioritizing lung cancer research and established the first federally-funded lung cancer research pipeline. We secured representation on several state cancer plans to ensure the entire continuum of care is available at the state level. We launched the first-ever "stigma-busting", award-winning education campaign reaching multiple millions with follow-on lung cancer risk and screening education campaigns to continue the positive national dialogue about our disease. We delivered support to thousands of newly diagnosed families to improve outcomes and mobilize local activists through Shine a Light – the world's largest awareness event for lung cancer – as well as Lung Love Run/Walk and the annual National Lung Cancer Survivor Summit in Washington, D.C. We secured lung cancer screening for those at high risk as the newest preventive service under the Affordable Care Act and covered by private insurance and Medicare/Medicaid. Despite these milestones, there is much more to be done. Lung cancer remains the leading cause of cancer death. Of those diagnosed, 2 out of 3 will be a former smoker, and 1 out of 4 will be a never smoker with the majority being women. With additional resources, we can bring about the most profound life-saving change ever for lung cancer -- and cancer overall since we represent almost 1/3 of all cancers. For example, we can educate the 90 million current and former smokers about risk and screening, as well as how screening can help current smokers to quit. We can advocate for and secure additional funding for research at the state and federal level fighting for the screening and treatment programs that save lives and the research that brings us closer to the cures. We can expand our National Lung Cancer Support Group Network to ensure that newly diagnosed patients and their families know
that they are not alone and there is a community that cares for them too. And we will expand our National Screening & Care
Centers of Excellence Network to ensure the rapid implementation of responsible screening that saves lives, improves
healthcare and propels research in ways we have never seen before.