2016 Annual Report



# catalyst for change

**人LUNG**EVITY



JUST AS THE BUTTERFLY EFFECT STATES THAT A SINGLE EVENT HAS THE ABILITY TO EFFECT MAJOR CHANGES, LUNGEVITY, THROUGH ACTIONS LARGE AND SMALL, HAS BEEN A CATALYST CREATING CHANGES THAT ARE INCREASING OPTIONS AND IMPROVING OUTCOMES FOR PEOPLE AFFECTED BY LUNG CANCER.



# innovate transform empower engage

LUNGevity is changing the way people are living with lung cancer.

We are accelerating scientific advances to patients through innovative translational research into early detection and new treatment options.

We are transforming how patients will be treated by bringing together the scientific, medical, corporate, and government communities to find new ways to remove barriers to access to care.

We are empowering patients and caregivers with exceptional educational resources and timely information about advances in research and treatment options.

We are engaging communities of support, both financial and emotional. These communities increase awareness about lung cancer, raise valuable funds for research, and provide strength and support for survivors.

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Andrea Ferris

Dear Friends,

Real progress for people living with lung cancer continues to build on the major advances of these past few years. With our patient-centric focus and commitment to funding impactful science, LUNGevity is transforming the field of lung cancer. Our strategic initiatives and our investment in impactful research are working to extend patients' lives and quality of life post-diagnosis.

LUNGevity's scientific research program funds studies that have the potential to revolutionize outcomes for those diagnosed with lung cancer. With our strategic approach in two priority areas—finding lung cancer early and treating it more effectively—our research speeds breakthroughs to patients so that people with lung cancer can live longer and better lives.

In 2016, we renewed our commitment to funding innovative and impactful science. Highly promising projects funded in early detection include using a novel imaging technique to complement tissue biopsies in the determination of early-stage lung cancer and investigating how normal lung cells acquire changes in their DNA to form premalignant lesions, with the goal of developing a biomarker to predict development of squamous cell lung cancer. In targeted therapies, a project is exploring how small cell lung cancer treatment. Our mentored Career Development Awardees continue to show excellent progress in their research as well as in their development as independent researchers.

This year, the LUNGevity Scientific and Clinical Roundtables brought together government agencies, industry partners, clinicians, and patients to streamline the design and execution of clinical trials and expand patient access to cutting-edge therapies.

LUNGevity knows that informed patients who are active participants in their care can have improved outcomes. We empower all people navigating a lung cancer diagnosis by providing easily accessible, accurate, and up-to-date resources. Our commitment to their well-being drives us to strengthen our peer-to-peer and online support programs.

Great change cannot occur without the unwavering dedication of supporters like you. Your contributions allow us to continue our essential work, and are appreciated by all of us working for a better future for those affected by lung cancer.

We greet 2017 with great optimism and determination, as we strive toward a world where no one dies of lung cancer. With each passing year, your support is making our goal more attainable.

Sincerely,

Andrea Ferris President and Chairman

# innovate

Our researchers are working on finding new, non-invasive tools to detect lung cancer in all populations and on NOVEL WAYS TO DIAGNOSE, TREAT, AND PREVENT its recurrence. The research program is a crucial factor in MOVING THE SCIENCE FORWARD TO IMPROVE OUTCOMES for people living with lung cancer. LUNGEVITY-FUNDED RESEARCHERS ARE WORKING ON BETTER WAYS TO DETECT, DIAGNOSE, AND TREAT LUNG CANCERS AND PREVENT THEIR RECURRENCE. LUNGevity invests millions of dollars in translational scientific research because we know it saves lives. Our two-part, strategic approach to funding research is designed to improve patient outcomes by finding lung cancer early and developing more effective treatments.

LUNGevity is the only nonprofit with a long-term programmatic focus on **EARLY DETECTION**, to find lung cancer before it spreads. Today, only 16% of people with lung cancer are diagnosed in the earliest stage, when the disease is most treatable. Unfortunately, there is no recommended screening test for lung cancer for those who do not fit the profile of a high-risk smoker.

**OUR ULTIMATE GOAL** is to develop a reliable, non-invasive, and broadly available test for lung cancer that can detect the disease early for everybody.

In September 2016, the SU2C-LUNGevity-American Lung Association Lung Cancer Interception Dream Team was announced, building on the Foundation's more than seven years of strategic investment in early-detection research. The Dream Team will be the first of its kind to focus research on lung cancer early detection and interception.

We also fund research to find more effective treatment approaches to get the right treatment to the right patient at the right time, and to understand why cancer becomes resistant to treatment. More efficient therapies will not only help more people survive, but will enable them to live well with lung cancer.

LUNGevity attracts the best and brightest scientific investigators through our CAREER DEVELOPMENT PROGRAM, enabling researchers early in their careers to pursue their research projects. These awardees receive financial support as well as valuable mentoring and training to propel their successful careers forward.

# LUNGEVITY-FUNDED RESEARCH PROGRESS

The talented investigators we fund are conducting important studies resulting in new discoveries on how to detect and treat lung cancer. From targeting mitochondria to block the energy centers of cancer cells to identifying novel biomarkers and developing technologies to predict response to drugs, these science program awardees are accelerating treatment options to patients.

#### **Targeting Energy Metabolism in Cancer Cells\***

Navdeep Chandel, PhD Northwestern University Feinberg School of Medicine



LUNG CANCER

Mitochondria are the powerhouses, or energy generators, of a cell. It has been known for decades that cancer cells produce energy differently than normal cells, and this may be due to changes in their mitochondria. Dr. Navdeep Chandel is investigating energy production by cancer cells. With the help of funding from LUNGevity, his team studied lung cancer in mice with a mutation in the KRAS gene. They found that blocking mitochondrial function inhibited the growth of lung cancer in these mice. Dr. Chandel's pioneering research has increased our understanding of how mitochondria assist KRASpositive lung cancer cells in their uncontrolled growth. This paradigm-shifting work has also led to a new area of cancer research—how we can target mitochondria and block the energy centers of cancer cells. Dr. Chandel was recognized for his work by receiving the National Cancer Institute Outstanding Investigator Award, which provides continuous funding for seven years.

#### Identifying which stage I and II lung cancer patients benefit from adjuvant chemotherapy

David Carbone, MD, PhD The Ohio State University

John Minna, MD The University of Texas Southwestern Medical Center

Ignacio Wistuba, MD The University of Texas MD Anderson Cancer Center



Use of computerized tomography (CT) screening helps detect stage I and stage II lung cancer. Patients with localized lung cancer usually undergo surgery to treat their cancer. Sometimes, the cancer comes back. Using adjuvant chemotherapy (post-surgical chemotherapy) can prevent the cancer's return. Dr. Carbone's team is studying how we can identify which stage I and II patients may benefit from adjuvant chemotherapy. With the LUNGevity award, their team has discovered that cancer cells from patients who respond to adjuvant chemotherapy produce higher amounts of a protein called SMARCA4 than those who do not respond. This work has identified SMARCA4 as a novel biomarker for predicting response to chemotherapy after surgery in localized non-small cell lung cancer (NSCLC).

### "LUNGevity's Translational Research Program is driving research results out of laboratories and into the clinics."

Charles M. Rudin, MD, PhD Professor and Chief, Thoracic Oncology Service Memorial Sloan Kettering Cancer Center Chairman of the LUNGevity Scientific Advisory Board



\* Funded equally by LUNGevity Foundation and this group of co-funders: Respiratory Health Association of Metropolitan Chicago/Arkansas Respiratory Health Association/Breathe California of Los Angeles County/Breathe California of the Bay Area/Breathe New Hampshire



## LUNGEVITY-FUNDED RESEARCH PROGRESS, continued

# Learning how lung cancer cells outwit EGFR tyrosine kinase inhibitors

Lecia V. Sequist, MD Massachusetts General Hospital

Jeffrey Engelman, MD, PhD Massachusetts General Hospital

Joel Neal, MD, PhD Stanford University

# DETERMINING MECHANISMS OF RESISTANCE TO NEXT-GENERATION EGFR INHIBITORS

Patients whose lung cancer tests positive for an EGFR mutation are typically treated with drugs called tyrosine kinase inhibitors (TKIs). Despite a promising response at the beginning of treatment, the lung cancer develops resistance to the TKIs, a phenomenon known as acquired resistance. The focus of Dr. Lecia Sequist's LUNGevity-funded project is to determine how lung cancer cells outwit EGFR TKIs such as erlotinib, gefitinib, and afatinib. Her team has established that lung cancer cells often develop a second mutation—the T790M mutation—in the EGFR gene. This mutation allows lung cancer cells to escape the growth-blocking effects of TKIs. Dr. Sequist and her colleagues have also found that patients with this mutation respond to the newer third-generation EGFR TKIs. In addition, they have developed technology that can identify which EGFR-positive lung cancers will develop acquired resistance. Dr. Seguist and her team's ultimate goal is to match an EGFR-positive lung cancer patient to the right treatment at the right time.



**Meredith Tennis, PhD** University of Colorado, Denver

#### BIOMARKERS FOR TARGETED LUNG CANCER CHEMOPREVENTION

Lung cancer progression begins when normal cells acquire small changes that make them more likely to become cancerous. Chemoprevention uses drugs to stop pre-cancerous cells from developing into fullblown cancer. Dr. Meredith Tennis is studying chemoprevention of lung cancer in high-risk populations, such as former and current smokers. With funding from LUNGevity, she investigated two already-FDAapproved drugs (pioglitazone and iloprost) that reduce the development of lung cancer in mice in response to cigarette carcinogens. Importantly, her research has found several proteins that are useful biomarkers for predicting who will respond to the two drugs, setting the stage for personalized chemoprevention trials.



LUNGevity is proud that 48 of our past and present awardees and eight members of the LUNGevity Scientific Advisory Board (SAB) presented their work at the 2016 American Association for Cancer Research Annual Meeting.



### 2016 CAREER DEVELOPMENT AWARDEES TACKLE UNMET NEEDS IN LUNG CANCER

The LUNGevity Career Development Awards program advances a new generation of outstanding lung cancer researchers. LUNGevity's 2016 cohort of scientists is studying:

- · How to predict which premalignant lesions will progress to squamous cell lung cancer
- How to improve the diagnosis of early-stage lung cancer
- How to make small cell lung cancer cells sensitive to chemotherapy

#### Developing a biomarker signature to predict development of squamous cell lung cancer



#### Joshua Campbell, PhD Boston University

While premalignant lesions in the airway can be detected by a technique called autofluorescence bronchoscopy, it is not currently understood why

and how some of these lesions progress to squamous cell lung cancer, a type of non-small cell lung cancer, while others do not. An ability to identify the lesions that are going to progress before they grow to invasive cancer would allow clinicians to intervene earlier and should reduce the number of squamous cell deaths. Dr. Joshua Campbell will use DNA sequencing to identify mutations in premalignant lesions from the airways of high-risk smokers that have been sampled over time. He will determine whether the presence of types of mutations can predict progression or regression of these lesions. The ultimate goal of Dr. Campbell's research is the development of an early-detection biomarker that will predict which premalignant lesions will go away and which will progress to cancer.

# Improving diagnosis of early-stage lung cancer with novel imaging tools\*



#### Lida Hariri, MD, PhD Massachusetts General Hospital

A tissue biopsy is required to make a definitive diagnosis of lung cancer. Unfortunately, low-risk methods of biopsy, such as bronchoscopy, are

often not able to adequately sample targeted nodules when they are small and/or difficult to navigate to. If a diagnosis cannot be made, patients must undergo a repeat biopsy or even surgery. Dr. Lida Hariri's project aims to dramatically improve lung cancer diagnosis with a low-risk biopsy by using a novel high-resolution imaging technique called Optical Coherence Tomography (OCT). Dr. Hariri will use OCT to perform virtual optical biopsies, ultra-sensitive imaging of early-stage lung cancers to complement the standard tissue biopsies. Her research could result in a powerful new bronchoscopy tool that could reduce unnecessary risky procedures, eliminate delays in diagnosis, and allow earlier therapy initiation.

# Understanding chemoresistance and identifying novel targets in small cell lung cancer



#### Jonathan Lehman, MD, PhD Vanderbilt University Medical Center

Small cell lung cancer represents approximately 15% of all lung cancers. Chemotherapy has been the mainstay

for treatment of small cell lung cancer for the past three decades. Small cell lung cancer responds well to initial treatment, but recurs frequently and aggressively. No targeted therapy is available for small cell lung cancer patients. Dr. Jonathan Lehman has identified that small cell lung cancer is heterogeneous—not every cell in the cancer is the same. He has found at least two types of cells in small cell lung cancer from patients. These two types of cells respond differently to chemotherapy. Dr. Lehman will characterize these two types of cells using a novel single-cell analysis technique called mass cytometry. His research will identify how we can better target the two cell types in order ultimately to develop targeted therapy for small cell lung cancer.

\* Funded in part by Upstage Lung Cancer

# PAVING THE PATH TO TARGETED THERAPY FOR SMALL CELL LUNG CANCER

A conversation with LUNGevity Career Development Awardee Dr. Lauren Averett Byers

LUNGevity created the Career Development Award (CDA) program in 2012. This program provides substantial funding to support future research leaders who will keep lung cancer research dynamic with new ideas and approaches. Dr. Lauren Averett Byers was among the first to receive a CDA. This award helped to jump-start Dr. Byers' career as an independent lung cancer investigator.



Dr. Byers' research focuses on a significant unmet need in lung cancer—personalized treatment for small cell lung cancer, for which therapy options are limited. While

small cell lung cancer initially responds well to chemotherapy, the cancer often comes back with an equal force. Dr. Byers is studying how small cell lung cancer becomes chemoresistant and how to better target it with combination therapies.



"As a physician-scientist, it's extremely gratifying for me to see that my patients will have more options for treatment."

Lauren Averett Byers, MD The University of Texas MD Anderson Cancer Center

# How did you become interested in cancer research?

I spent one year of medical school at the National Institutes of Health studying lymphoma. The research team at the NIH made a landmark discovery—that different tumors have different sets of genes turned on, impacting the behavior of a cancer and, therefore, response to a treatment. It also explained why one group of patients did really well with a treatment while another group did not. I became interested in developing personalized treatments for cancer patients. I went to MD Anderson, where I started as a medical oncology fellow under the mentorship of [LUNGevity Scientific Advisory Board member and awardee] Dr. John Heymach, and developed a research program in small cell lung cancer.

# What was the focus of your LUNGevity CDA award?

We found that a protein called PARP is present at high levels in small cell lung cancer. We were able to demonstrate that if you blocked PARP in small cell, you could get the cells to stop growing. We saw that small cell tumors shrank in mice when we treated them with PARP-blocking drugs. We had a new targeted agent for small cell. These findings opened the door for several clinical trials with PARP inhibitors in small cell.

And as we know, targeted therapy works best in a subset of tumors. So the logical second part of the CDA project was identifying those small cell lung cancers that respond well to PARP inhibitors and determining why some did not. Our ultimate goal is to identify biomarkers that predict responses to PARP inhibitors and determine how best to combine them with other agents to make them even more potent. "The LUNGevity CDA was absolutely essential for getting my lab started. It provided me the funding to do some really exciting work around an unexpected finding that we had made about the PARP protein in small cell lung cancer. Chemotherapy has been the standard of care for small cell for the last three decades. The LUNGevity funded-project led to the discovery of the PARP protein as a novel target in this disease."



Lauren Averett Byers, MD, The University of Texas MD Anderson Cancer Center

# How did the LUNGevity award boost your research?

Funding from LUNGevity was essential in launching this new area of investigation in small cell lung cancer—PARP inhibitors and other drugs that target DNA repair.

Traditionally, we have always treated small cell lung cancer as one disease. So everyone gets the same treatment-chemotherapy and radiation. Much like in non-small cell lung cancer, we are now seeing that there are really different types of small cell lung cancer at the gene level. Understanding which genes are turned on in an individual patient's small cell lung cancer will be really important for knowing from which drugs and which targeted therapy each patient might get the most benefit. The LUNGevity award helped us start in this new direction for research and laid the foundation for the NIH R01 grant we recently received. This follow-up project will investigate novel combinations of PARP inhibitors with other inhibitors of the DNA damage response to develop personalized, targeted approaches for the treatment of small cell.

Apart from funding this research, LUNGevity also gave me access to a great community of senior lung cancer researchers. LUNGevity convenes several annual meetings that bring together lung cancer experts. As a CDA, I was an *ex officio* member of the LUNGevity Scientific Advisory Board and participated in their meetings. Through these engagements, I have gotten to know the leaders of the field personally, many of whom have become incredible mentors who have guided my research. I have also developed fruitful collaborations with my fellow awardees.

# How has your LUNGevity project impacted the treatment of small cell lung cancer?

As someone who takes care of patients as well as does laboratory research, it was exciting to see a discovery in the laboratory translate rapidly into clinical trials. I can think of at least ten clinical trials that are now investigating PARP inhibitors, either alone or in combination.

The job of PARP is to repair damage caused to DNA. One of the reasons that chemotherapy and radiation work in small cell lung cancers is because they cause DNA damage. But cancer cells are shrewd. They have figured out ways to repair the damage and become resistant to these conventional therapies. One of the ways by which small cell lung cancer cells escape damage is by making lots of PARP protein. So if we find ways to combine the PARP inhibitors, which prevent the cancer cells from being able to repair the DNA damage with chemotherapy drugs such as temozolomide, for example, we can really boost the effect of both the chemotherapy and the PARP inhibitors. Small cell patients may now have access to a whole new class of targeted agents for small cell.

## SCIENTIFIC ADVISORY BOARD\*

LUNGevity strategically invests funds with the support of a world-class Scientific Advisory Board composed of leaders in their respective fields. This board meets twice a year to share new scientific developments, discuss research strategy, oversee ongoing funded projects, and review grant proposals. These leaders in the fields of proteomics, biostatistics, radiology, immunotherapy, and others are instrumental in improving the outcomes for lung cancer patients.

#### Denise R. Aberle, MD

David Geffen School of Medicine at UCLA Professor and Vice Chair of Research, Radiology

#### Nasser K. Altorki, MB, BCh

NewYork-Presbyterian/Weill Cornell Medical Center Professor of Cardiothoracic Surgery Chief, Division of Thoracic Surgery

#### Philip D. Bonomi, MD

Rush University Medical Center Alice Pirie Wirtz Professor of Medical Oncology Director, Division of Hematology-

Oncology

#### Julie R. Brahmer, MD

The Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins Director of the Thoracic Oncology Program

Associate Professor of Oncology

Director, Upper Aerodigestive (UAD) Program

Interim Director, Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins Bayview

#### David P. Carbone, MD, PhD

**The Ohio State University** *Professor, Division of Medical Oncology* 

Barbara J. Bonner Chair in Lung Cancer Research

Director of the Thoracic Oncology Center

International Association for the Study of Lung Cancer (IASLC) President

\* As of June 30, 2016

#### Steven M. Dubinett, MD

David Geffen School of Medicine at UCLA Chief, Division of Pulmonary and Critical Care Medicine

Senior Associate Dean for Translational Research Associate Vice Chancellor for Research Director, Clinical and Translational Science Institute (CTSI)

#### Edward W. Gabrielson, MD

Johns Hopkins University School of Medicine Professor of Pathology and Oncology

#### John V. Heymach, MD, PhD

The University of Texas MD Anderson Cancer Center Professor and Chairman, Department of Thoracic/Head and Neck Medical Oncology, Division of Cancer Medicine

#### **Robert L. Keith, MD**

**University of Colorado Denver** *Professor of Medicine and Cancer Biology* 

**Denver VAMC** Associate Chief of Staff-Research

#### Pierre P. Massion, MD

Vanderbilt-Ingram Cancer Center Cornelius Vanderbilt Chair in Medicine

Vanderbilt University School of Medicine Professor of Medicine and Cancer Biology Director, Thoracic Program

#### Charles M. Rudin, MD, PhD

Memorial Sloan Kettering Cancer Center Professor and Chief, Thoracic Oncology Service

#### Lawrence H. Schwartz, MD

Columbia University Medical Center James Picker Professor and Chairman, Department of Radiology

NewYork-Presbyterian/ Columbia University Medical Center Radiologist-in-Chief

#### Lecia V. Sequist, MD, MPH

Harvard Medical School The Landry Family Associate Professor of Medicine

Massachusetts General Hospital Cancer Center

#### Steven J. Skates, PhD

Harvard Medical School and Massachusetts General Hospital Associate Professor

#### Avrum E. Spira, MD, MSci

**Boston University** Professor of Medicine, Pathology and Bioinformatics

Alexander Graham Bell Professor in Healthcare Entrepreneurship

Chief, Section of Computational Biomedicine

Director of the Boston University Cancer Center

# transform

We believe that it is imperative to include **THE PATIENT VOICE** in research, treatment decisions, and public policy. By uncovering and recognizing patient needs and preferences, LUNGevity is **CHANGING HOW LUNG CANCER PATIENTS WILL BE TREATED**.

#### LUNGEVITY IS AT THE FOREFRONT OF ADVANCING A TRANSFORMATION THROUGH OUR PATIENT-FOCUSED RESEARCH AND REGULATORY

**INITIATIVES.** Progress in the lung cancer treatment landscape is advancing at unprecedented rates. However, most trials and therapies are developed without the direct input of the patients who are supposed to be served. The shifting model in medicine and drug development is moving away from the traditional model of assuming patient preferences based on the input of proxies and toward one where the patients themselves—the consumers—are providing this input.

LUNGevity conducts research to understand how patients are now **living** with lung cancer. We are changing the paradigm in lung cancer from assumptions being made about patient wishes to evidence-based conclusions about patient desires.

Our main goal is to ensure that lung cancer trials, treatments, and medical practice are focused on meeting the true needs of patients and their families.

## PROJECT TRANSFORM

With several treatment options available to advanced-stage non-small cell lung cancer patients comes an unaddressed question: What do patients really want from their treatment? Better quality of life? Extended survival? Other benefits? PROJECT TRANSFORM—a collaboration between LUNGevity and Johns Hopkins School of Public Health—seeks to understand these treatment preferences of lung cancer patients. It encompasses core principles of patient-centered outcomes research (PCOR), and provides a robust data-driven way to capture patient preferences. The pilot phase of the study was completed in 2016, and we are now launching the nationwide, large-scale patient preference study.



We are changing the model in lung cancer from assumptions being made about patient wishes to evidence-based conclusions about patient desires.

# SCIENTIFIC AND CLINICAL RESEARCH ROUNDTABLES

LUNGevity Foundation hosted two Scientific and Clinical Research Roundtables in 2016. These roundtables convened key stakeholders from across the lung cancer ecosystem senior-level representatives from regulatory and government agencies, pharmaceutical industry partners, patient advocacy organizations, and scientific and clinical key opinion leaders—to candidly discuss challenges and opportunities in streamlining clinical trials and making them more accessible to patients. The 2016 roundtables identified three priority areas:

- Expanding eligibility criteria for lung cancer clinical trials
- Streamlining reporting of suspected unexpected serious adverse reactions (SUSARs) in lung cancer clinical trials
- Potential for use of a historic control arm within novel trial design for lung cancer

The work from these roundtables is continuing in 2017 with the goal of establishing revised guidlines and streamlining reporting requirements to accelerate clinical trials and make them more accessible to patients.

Through qualitative and quantitative research, LUNGevity seeks to uncover gaps in information, misperceptions about patient attitudes, and areas of unmet need. We then incorporate the lung cancer patients' preferences and experiences into the development of relevant policy, treatments, and research protocols.





"Rather than accepting the status quo, we are establishing a new paradigm for collaboration among government agencies, industry partners, clinicians, and patients to work together to improve outcomes for people diagnosed with lung cancer."

Andrea Ferris LUNGevity President and Chairman

## TAKE AIM INITIATIVE

Coordinated and timely biomarker testing is essential to support informed treatment decisions for non-small cell lung cancer patients. However, many patients are never tested, and, when they are, clinicians too often don't receive the results in a timely fashion to develop the most appropriate treatment plans for patients.

Building on work streams begun in 2015 as part of the Take Aim Initiative, LUNGevity convened a second stakeholder roundtable with leaders representing a cross-section of professional societies, patient advocacy groups, clinicians, and biopharmaceutical companies active in lung cancer research, education, and patient care. Five specific areas emerged as top priorities from the roundtable discussion:

- Address reimbursement of next-generation sequencing (NGS) for determining mutations
- Coordinate biomarker awareness and education programs to create a unified message for both patients and healthcare providers
- Advocate and educate about the importance of pulling core tissue biopsies in order to obtain enough tissue to perform complete biomarker testing
- Work with healthcare professionals (HCPs) to establish Best Practices in tissue-sparing techniques
- Ensure that patients and practitioners can understand pathology reports

Building on these priority areas, LUNGevity will spearhead efforts toward the ultimate goal of ensuring that all patients diagnosed with non-small cell lung cancer have their cancer biomarkers profiled in a timely way.

# empower

**PATIENTS WHO ARE EDUCATED** about their diagnosis are known to have improved outcomes. LUNGevity provides information, resources, and support patients need to be **ACTIVE PARTICIPANTS** in their healthcare decisions.

#### LUNGEVITY HELPS PATIENTS MANAGE THEIR LUNG CANCER DIAGNOSIS.

We develop timely education materials and unique tools to address patient needs at any time along their lung cancer journey. From the comprehensive, up-to-date **LUNG CANCER 101** website with an extensive glossary of terms to downloadable booklets and animated videos on types of lung cancer and treatment options, expert blogs, and online networks, LUNGevity empowers patients to be active participants in their healthcare decisions.

Participating in a clinical trial can extend patient lives, but finding a trial for which a patient qualifies can be a daunting challenge. LUNGevity's online **CLINICAL TRIAL FINDER** is an effective resource that enables patients to more easily find clinical trials that match their individual situation, including type of lung cancer, treatment history, and geographic location.

LUNGevity is developing new tools to help patients and their caregivers with disease management. The **LUNGEVITY LUNG CANCER NAVIGATOR** is a mobile app that allows patients to receive customized information on their specific diagnosis while communicating with their support network and managing their care.

In 2017, we launched the **LUNG CANCER HELPLINE**, in partnership with CancerCare<sup>®</sup>. This free service provides access to a team of professional oncology social workers who are trained to effectively address the distinct financial, emotional, practical, and physical challenges of lung cancer patients and caregivers. We continue to build strategic collaborations to provide tools and resources that patients need to make more informed healthcare decisions.



LUNGevity empowers patients to be active participants in their healthcare decisions.

"My first attendance at the HOPE Summit gave me exactly what I was looking for—HOPE. After a shocking lung cancer diagnosis, overwhelmed with surgery, treatments, and scary survival odds—the sense of community and positive outlook I experienced during the weekend changed my life. Today, I know that I am not alone."



Jose Rodriguez Lung cancer survivor

Our ongoing support programs provide hope and strength to people dealing with a lung cancer diagnosis. We offer **PEER-TO-PEER SUPPORT** through our LifeLine and Clinical Trial Ambassador programs by matching patients and caregivers to Support Mentors who have had similar experiences. LUNGevity's Lung Cancer Support Community (LCSC), an online lung cancer support network, is a moderated message board where people can share the latest lung cancer information and resources. With over 450,000 posts, a patient or family member can find information on all aspects of managing lung cancer. Online Survivor and Caregiver Resource Centers make available helpful information and trusted resources tailored to the unique needs of lung cancer patients and their families.

**LUNGEVITY HOPE SUMMIT** survivorship conferences convene the largest groups of lung cancer survivors and caregivers in the country. These conferences are specifically designed to teach people how to live well with lung cancer and build a community of hope.

This comprehensive, one-of a kind survivorship conference provides information on everything from advocacy to research to nutrition and caregiving, while creating an instant community of fellow survivors.

2016 was a banner year for LUNGevity's HOPE Summit survivorship conferences. The 6th annual national HOPE Summit in Washington, DC, saw a record number of attendees for a lung cancer survivor conference—close to 300 attendees, including more than 200 lung cancer survivors! Participants came from across the country and Canada, as well as from Brazil and Australia.

With one-day HOPE Summits in Columbus, Ohio; Dallas, Texas; and Detroit, Michigan, LUNGevity empowered more survivors and caregivers than ever to live better with lung cancer.





















The mood of this year's conference was inspirational, empowering, and hopeful with survivors and caregivers sharing stories and information, while welcoming new attendees and greeting old friends. Highlights included:

- The addition of a third day for advocacy education, in which members of the media and leading lung cancer advocates shared their insights with fellow survivors. This fast-paced day included talks by the director of Government Affairs for AACR (American Association for Cancer Research); the program manager of the Department of Defense Lung Cancer Research Programs on how patients and advocates can participate in peer review of lung cancer research grants; a panel of top journalists and media experts on how to get one's story told by the press; and a panel on the use of social media for advocacy that included Dr. Nathan Pennell of the Cleveland Clinic, a brilliant doctor and a social media guru.
- Keynote address by Dr. Gideon Blumenthal, Clinical Team Leader, Thoracic Oncology Center for Drug Evaluation and Research (CDER) at the FDA, who discussed the status of lung cancer drugs and the purpose of fast-tracking treatments through regulatory approval. We also heard from SAB member and IASLC president Dr. David Carbone, who shared his own experience with cancer and how it informs the way he works with lung cancer patients.
- Drs. Philip Bonomi from Rush Medical Center, J.T. Poirier from Memorial Sloan Kettering Cancer Center, Susan Moffat-Bruce from The Ohio State University, and Lecia Sequist from Massachusetts General Hospital addressed topics ranging from finding the right doctor to what advances in research mean for patients.
- Former NFL player and lung cancer advocate Chris Draft delivered a moving and inspirational closing address.

PHOTO CAPTIONS 1) A lung cancer survivor at the National HOPE Summit shares his story with attendees. 2) Returning HOPE Summit survivors reunite. 3) A lung cancer survivor and caregiver share a moment. 4) Making new friends and reconnecting with old ones. 5) HOPE Summit attendees capture memories of this special weekend. 6) HOPE Summit speakers Dr. Gideon Blumenthal of the FDA (left) and Dr. Lecia Sequist of Massachusetts General Hospital (center) with lung cancer survivor Sara Whitlock.
7) LUNGevity is grateful to the many sponsors of the HOPE Summit, who recognize the value of these survivorship conferences to the lung cancer community. 8a/8b) Attendees split up to discuss topics of specific interest to them. 9) Survivors and caregivers hear from medical and healthcare professionals about the latest advances in early detection and treatment, clinical trials, living with lung cancer, and more. 10) Advocate Chris Draft and friends go for a lung cancer touchdown!

### PATIENT VOICES

"When I was diagnosed as a fit 29-year-old, I didn't know that it was even possible for a never-smoker to get lung cancer. Now I want to improve treatments and outcomes for everyone fighting this disease."

ALLEN LI Stage 4 EGFR+, diagnosed 2015, with care partner AMY LI





"LUNGevity is committed to improving patient access to the clinical trials that can increase survival as well as quality of life."

LINNEA OLSON Stage 4, diagnosed 2005

*"LUNGevity empowers patients with the education and resources they need to be active participants in their healthcare decisions."* 

**YARIV "DOLIO" KAFRI** Stage 4, diagnosed 2013





"We need the research—without knowledge, we can't fight lung cancer. That's why LUNGevity is so important—they fund the research for new treatments and early detection."

**TRACY MURPHY** Stage IIIB, diagnosed 2009

# engage

LUNGevity programs **BUILD, MOTIVATE, AND MOBILIZE** the lung cancer community. Together with survivors, caregivers, families, and volunteers, we are creating a **NATIONAL COMMUNITY TO SUPPORT** people affected by lung cancer.

#### LUNGEVITY IS DEDICATED TO BUILDING THE LUNG CANCER

**COMMUNITY.** By creating bridges between patients, their families, and other stakeholders, we will have the greatest impact on improving outcomes for people living with lung cancer.

LUNGevity's **BREATHE DEEP** grassroots series is the nation's largest network of local lung cancer events. These vibrant events engage the whole community— individuals, healthcare centers, businesses, and civic groups—and provide strength and hope for patients and families affected by lung cancer.

Athletes from around the country are joining **TEAM LUNGEVITY**. Runners, bikers, and swimmers can choose to join one of our official charity partner races, or secure their own spot in their race of choice. We provide training plans and fundraising tools, along with other incentives, to help athletes meet their goals—both on the course and in their fundraising campaign.

In 2016, volunteers created new **DO-IT-YOURSELF** ways, such as a softball tournament and a wine tasting, to support our efforts. Together with Breathe Deep, they are helping to create a stronger national movement to change outcomes for people living with lung cancer.

LUNGevity offers volunteers a variety of ways to be successful in raising awareness in their communities. We provide a downloadable Lung Cancer **ADVOCACY TOOL KIT** and materials for distribution at local events. Advocates with strong social media followings can volunteer to be **SOCIAL MEDIA AMBASSADORS** and can submit blog posts to reach a broader audience with their personal experience with lung cancer.

PHOTO CAPTIONS 1) Breathe Deep participants hit the road to help stop lung cancer. 2) Family and friends come out together at Breathe Deep Michigan in support of "Grandma." 3) Twelve lung cancer survivors on the stage at Breathe Deep North Shore! 4) Proud members of the lung cancer community at a Breathe Deep event. 5) Kids find that their participation makes a difference. 6) We rely on dedicated volunteers like these to ensure successful Breathe Deep events. 7) Special guest, the Oriole Bird, at Breathe Deep Baltimore. 8) LUNGevity bracelets are available at Breathe Deep events. Wearing one starts conversations about the need for lung cancer research. 9) A few raindrops didn't stop our Breathe Deep participants from walking for the cause. 10) Balloons with names of loved ones written on them are released into the sky as part of a moving ceremony at a number of Breathe Deep events. 11) Event participants put themselves in the middle of the lung cancer research, education, and support picture.



















BREATHE TO ERD LUNG CANCER



UNGevity.org/boca



















LUNGevity special events attract business leaders, philanthropists, survivors, and scientists to accelerate progress in lung cancer research. Guests celebrated scientific advances for people with lung cancer at the **CELEBRATION OF HOPE GALA IN NEW YORK CITY**, honoring Lilly Oncology and lung cancer survivor and advocate Richard Heimler. Attendees danced to New Orleans-inspired music at the **MUSICAL CELEBRATION OF HOPE GALA IN WASHINGTON, DC**, honoring Richard Pazdur, MD, for his meaningful work at the FDA on behalf of patients, and CEB, for its ongoing support of the lung cancer community.

Guests enjoyed a lively casino-themed evening at the **ANTE UP FOR HOPE FALL BENEFIT IN CHICAGO**. The evening's honoree was Patti Helfand, a lung cancer survivor and one of the seven founding members of LUNGevity. Their efforts laid the groundwork that propelled LUNGevity from a Chicago-born organization to the nation's leading lung cancer nonprofit.

PHOTO CAPTIONS 1) Newton Crenshaw, Vice President of the Oncology Business Unit, accepted the Hope Award for Corporate Leadership on behalf of Lilly Oncology at the NYC Celebration of Hope Gala. He is pictured here, fifth from the left in the back row, among Lilly colleagues. 2) LUNGevity Scientific Advisory Board Chairman Charles Rudin, MD, and LUNGevity President and Chairman Andrea Ferris chatted at the NYC Gala about the extraordinary pace of progress in lung cancer research. 3) Lisa and (the late) Jerry Sorkin, Vice Chair of the LUNGevity Board of Directors, at the DC Gala. 4) Lung cancer survivor Richard Heimler, accepting the Face of Hope Award at the NYC Gala for his tireless advocacy on behalf of all people affected by lung cancer and the meaningful change his efforts are making. 5) There was plenty of casino-game excitement at the "Ante up for Hope" Chicago Fall Benefit. 6) At the Chicago Fall Benefit, Patti Helfand, one of the founders of LUNGevity Foundation, received the Founders Award, for her leadership and passion to end lung cancer, from Mark Swerdlow, member of the LUNGevity Board of Directors. 7) DC Gala guests, with LUNGevity Scientific Advisory Board member Dr. Julie Brahmer, toast to better outcomes for lung cancer patients. 8) Guests fill the magnificent Andrew W. Mellon Auditorium for the Musical Celebration of Hope Gala in Washington, DC. 9) Honoree Richard Pazdur, MD, Director of the Office of Hematology and Oncology Products at the FDA, with presenter Greta Kreuz and Andrea Ferris.

# LUNGEVITY GRASSROOTS, BENEFACTOR, GALA, AND SPECIAL EVENTS

July 1, 2015-June 30, 2016

#### ALABAMA

• Breathe Deep Mobile

#### ARIZONA

- Breathe Deep Phoenix
- Breathe Deep Tucson

#### ARKANSAS

Breathe Deep Fayetteville

#### CALIFORNIA

- Breathe Deep Bay Area
- Breathe Deep San Diego
- Mollie's Country Kitchen Fundraiser—Laguna Niguel
- The Pearl Project—Los Angeles

#### CONNECTICUT

• Tom Bigler Memorial Softball Tournament—Danbury

#### DISTRICT OF COLUMBIA

- Breathe Deep DC
- LUNGevity's Musical Celebration of Hope Gala
- National HOPE Summit
- SoulCycle Ride for LUNGevity

#### FLORIDA

- Breathe Deep Boca Raton
- Lung Cancer Awareness Bracelet—Ft. Lauderdale

#### GEORGIA

- Breathe Deep Atlanta
- Breathe Deep Blue Ridge
- Total Wine & More Atlanta Wine-tasting Reception

#### ILLINOIS

- Breathe Deep Busse Woods
- Breathe Deep DuPage— Naperville
- Breathe Deep Kankakee
- Breathe Deep Lake Arlington— Arlington Heights
- Breathe Deep North Shore— Deerfield
- Breathe Deep Springfield
- Elizabeth Toscano Bat Mitzvah—Buffalo Grove
- John Whiteside/Beatrice Green Lung Cancer Walk & Fun Run—Arlington Heights

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- LUNGevity Foundation Fall Benefit—Chicago
- Pauline Moraco-Arredondo Walk & Rally—Chicago
- Rafters Restaurant Shave the Chef—Lena
- Team LUNGevity—Bank of America Chicago Marathon

#### INDIANA

 Susan Filson LC Awareness 5K—Lafayette

#### IOWA

• Breathe Deep Des Moines

#### MARYLAND

- Breathe Deep Baltimore
- Breathe Deep Columbia
- Woodlawn Fundraiser

#### MASSACHUSETTS

- Be Bold, Be Bald!-Boston
- Breathe Deep Boston

#### MICHIGAN

- 5K Walk at Uncle John's Cider Mill—Saint Johns
- Breathe Deep Michigan— Birmingham
- Breathe Deep South Lyon
- Detroit HOPE Summit
- Lung Cancer Fundraiser at California Pizza Kitchen—Troy

#### MINNESOTA

• 2016 Starbase Indy Conference—Minneapolis

#### MISSOURI

- Breathe Deep Kansas City
- Breathe Deep St. Louis

#### NATIONWIDE

- Breathe Deep Virtual Walk 11/11/15
- Breathe Deep Virtual Walk 5/15/16

#### NEW JERSEY

• Breathe Deep South Jersey— Pennsauken

#### NEW YORK

- Breathe Deep Albany
- Breathe Deep CNY—Liverpool
- Breathe Deep NYC

- Celebration of Hope Gala–NYC
- Golf with Me—Guilderland
- Paint Night!—Westbury
- Run as One–New York

#### NORTH CAROLINA

• ITRON Food Truck Rodeo— Wake Forest

#### оню

- BowTie Cause—Cincinnati
- Breathe Deep Cleveland
- Breathe Deep Columbus
- Breathe Deep Newark
- Columbus HOPE Summit
- Jackie's Tap Takeover (Cappy's Liquors)—Loveland

#### PENNSYLVANIA

- 4th Annual Open House IMO Geraldine Naylor—Millerstown
- Breathe Deep Greensburg
- Breathe Deep NEPA —Kingston
- Breathe Deep Philadelphia
- Breathe Deep Pittsburgh
- Hanover LCAM Fundraising

#### TENNESSEE

 Breathe Deep Nashville Stache and Lash 5K

#### TEXAS

- Breathe Deep DFW—Arlington
- Dallas HOPE Summit

#### UTAH

Breathe Deep Salt Lake City

Chip Kennett Memorial Golf

Total Wine & More McLean

Wine-tasting Reception

Tournament-Clifton

• Breathe Deep Seattle

• Ride to Ellen—Seattle

• Seattle Hope Summit

Frozen Yogurt Social—

#### VIRGINIA

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WEST VIRGINIA

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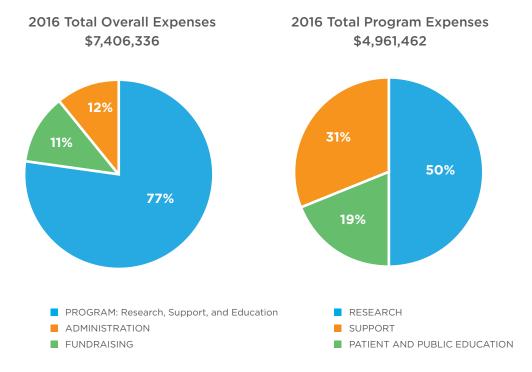
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## OVERALL FINANCIAL HEALTH

LUNGevity Foundation remained fiscally strong in 2016, thanks to a diverse set of donors. We were able to continue to grow our programs while adding support resources and new events, increasing the populations we serve.

The financial activities of LUNGevity Foundation were audited by Ostrow, Reisin Berk & Abrams, Ltd. For our complete audited financial statements, please visit our website at www.LUNGevity.org.



## 2016 TOTAL REVENUE: \$7,513,054

## SUMMARY OF PROFIT AND LOSS

June 30, 2016

	2016	2015
Revenues:		
Contributions and grants	\$ 4,211,258	\$ 3,682,539
Special events and other fundraisers	3,150,295	3,864,666
Interest and dividends	3,703	4,008
Donated goods and services	147,798	294,773
Total revenue	\$ 7,513,054	\$ 7,845,986
Expenses:		
Program services	\$4,961,462	\$5,044,038
Management and general	800,223	712,805
Fundraising	706,669	970,815
Special events	937,982	1,109,454
Total expenses	\$7,406,336	\$ 7,837,112
Change in net assets	106,718	8,874
Net assets:		
Beginning of year	\$3,072,016	\$ 3,063,142
End of year	\$ 3,178,734	\$ 3,072,016

## STATEMENT OF FINANCIAL POSITION

June 30, 2016

	2016	2015
Net assets:		
Cash and cash equivalents	\$ 803,775	\$ 1,497,146
Prepaid expenses	173,680	207,925
Accounts and grants receivable	1,322,204	351,910
Pledges receivable	1,306,268	1,705,235
Security deposits	14,752	14,752
Property and equipment, net	29,952	38,807
Total assets	\$3,650,631	\$ 3,815,775
LIABILITIES AND NET ASSETS Liabilities: Accounts payable	\$ 83,201	\$ 78,573
Accrued payroll and vacation liabilities	82,036	56,141
Grants payable	300,000	600,000
Deferred revenue	6,660	9,045
Total liabilities	\$ 471,897	\$ 743,759
Net assets:		
Unrestricted	\$ 437,963	\$ 1,366,781
Temporarily restricted	2,740,771	1,705,235
Total net assets	3,178,734	3,072,016
Total liabilities and net assets	\$3,650,631	\$ 3,815,775

## HOW TO GET INVOLVED

### THANK YOU FOR YOUR CONTINUED SUPPORT!

We hope you will join us in 2017! With the ongoing support of our donors and volunteers, LUNGevity is making an impact on the lives of people affected by lung cancer. This year, there are more ways than ever to get involved.

### PARTICIPATE IN A LUNGEVITY EVENT

Attend a Breathe Deep event near you and join hundreds of lung cancer advocates, survivors, and family members to help drive change for people diagnosed with lung cancer. You can volunteer, start a team, or create your own unique event!

## RAISE MONEY FOR LUNG CANCER RESEARCH AND SUPPORT

You can fundraise through a LUNGevity event or create a DIY event in your community. We can help you succeed. Participating in an endurance event? Team LUNGevity provides the tools to fundraise from friends and family. An online tribute fund is a meaningful way to honor someone impacted by lung cancer.

### RAISE AWARENESS FOR LUNG CANCER

LUNGevity has a wide variety of materials to help you be an active and effective advocate for those living with lung cancer. Download the Lung Cancer Advocacy Toolkit, read our online blogs, and sign up for our newsletter to keep up with the latest news.

For more information on any of these opportunities or to discuss any ideas you have about how LUNGevity can be more connected to your community, contact Becky Bull, Chief Development Officer, at bbull@LUNGevity.org.

## CONNECT TO OUR SUPPORT COMMUNITY AND RESOURCES

If you or a loved one is a lung cancer patient, LUNGevity offers many resources for you. The Lung Cancer Support Community online network and LifeLine Support Partner program will connect you with others at any stage of a lung cancer diagnosis. Considering a clinical trial? LUNGevity can match you with a Clinical Trial Ambassador who can share their experience. Our website has dedicated Survivor and Caregiver Resource Centers offering practical support for your physical and emotional well-being. Survivors and caregivers can also attend a HOPE Summit, a conference designed especially for you. Call the free LUNGevity Lung Cancer HELPLine (833-360-LUNG) to speak with professional oncology social workers about your emotional, practical, and information needs.

For more information on LUNGevity support programs, contact Katie Brown, VP Support and Survivorship Programs, at kbrown@LUNGevity.org.



## Jerome Daniel Sorkin

June 8, 1965-October 26, 2016

LUNGevity Foundation mourns the loss of beloved friend, advocate, and Vice Chairman of the Board, Jerry Sorkin. A three-time cancer survivor and never-smoker, Jerry was diagnosed with stage IV lung cancer in August 2007. He began working with LUNGevity Foundation in 2009 and joined the Board that same year. Jerry was the founding force behind Breathe Deep DC, the annual 5K walk that raises funds and awareness of the need for lung cancer research. Jerry's impact on LUNGevity's work is pervasive—his influence has been felt in all that LUNGevity has accomplished over the past seven years, and he is incredibly missed. Jerry was a powerful yet gentle ally in the ongoing battle against lung cancer. His dedication and selflessness have benefited so many in the lung cancer community.

In addition to his important role in accelerating progress and creating hope for lung cancer patients, Jerry was Executive Director, CEB in the Community, at CEB. He is survived by his wife, Lisa, and daughters, Emma and Claire, who were always by his side in all his efforts to change the dialogue about lung cancer and change the future for lung cancer patients. They joined him in making lung cancer research a life-motivating priority.

LUNGevity rededicates its efforts to finding cures and treatments in Jerry's memory.





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