

fresh air

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IN THIS ISSUE

Inhale for Life [page 1](#)

Enhancing Veteran Access to
Clinical Trials [page 1](#)

LUNGeVity's Take Aim Initiative
[page 2](#)

Reflections from the President
and CEO [page 2](#)

Board of Directors and Scientific
Advisory Board [page 2](#)

Tom Galli, Michael Marquis, and
Andre Owens Join LUNGeVity
Foundation Board of Directors
[page 3](#)

Two Evenings and One Weekend
Inspire the Lung Cancer
Community [page 4](#)

Getting Ahead of Inherited lung
Cancer [page 5](#)

Highlights of AACR 2018 [page 6](#)

Immunotherapy Given Before
Surgery May Help Early-Stage
Lung Cancer Patients [page 7](#)

Driving Reform in Clinical
Trials [page 8](#)

Upstage Lung Cancer [page 9](#)

2017 Fall Breathe Deep Event
Photos [page 10](#)

Chicago! Chicago! [page 11](#)

Upcoming Breathe Deep Spring
and Summer Events [back cover](#)

Inhale for Life

In November 2017, LUNGeVity launched a new awareness campaign to change the common perception of a lung cancer diagnosis. The campaign, Inhale for Life, utilizes video and social media to reach those living with lung cancer with the message that, thanks to new treatment options, people today are living longer and better with the disease.

Inhale for Life uses breathing to represent the connection among all of us — lung cancer patients and non-patients alike.

The campaign was launched through social media to coincide with Lung Cancer Awareness Month, supported in part by grants from Genentech and AstraZeneca. In addition to a video intercutting people taking deep breaths with facts about the disease, eight lung cancer survivors were highlighted with their personal stories. To date, the video has been viewed by over 365,000 people on Facebook alone, with over a thousand signing up to learn more.

A ten-second version of the public service announcement appeared before



holiday crowds on a digital billboard in Times Square, made possible through a grant from Bristol-Myers Squibb. It was also shown to crowds at the Daytona 500 NASCAR races in Florida.

Stay tuned for the next topic in the awareness

campaign series — on biomarker testing for people diagnosed with lung cancer. Biomarker testing can reveal information on whether there are changes in the cancer cells that can be targeted with specific drugs. Plans are also underway to launch a third effort on the importance of clinical trials.

When you see it, share it! You can help us spread awareness by “sharing” the campaign with your social media network.

Enhancing Veteran Access to Clinical Trials

Of the approximately 18,000 veterans diagnosed with lung cancer each year, about 8,000 of them are treated within the Veterans Health Administration (VHA) system.

Given the dramatic improvement over the past decade in treatment options for

lung cancer as well as the vital point of access to novel therapeutics that clinical trials provide, it is imperative to ensure that veterans have access to clinical trials as part of clinical care throughout their treatment. LUNGeVity Foundation is working with the VHA to prioritize this access. [continued on page 8](#)



March 16 marked the 10-year anniversary of my mother's death from lung cancer and the 10-year anniversary of my becoming a patient advocate. I got involved with lung cancer patient advocacy to help ensure that other people and families did not suffer the same fate that my mother and our family did.

During the past decade, we have witnessed unprecedented advancements in the science of understanding, diagnosing, and treating lung cancer. We have also seen the rise of impactful patient advocacy groups, a transformation in how patients are interacting with regulators, industry partners, and the healthcare system more broadly. Importantly, we have seen the birth of patient centricity in drug development and clinical trials. Patients are demanding to be heard. At LUNGeivity we strive to put the patient front and center in all we do and work to ensure that we help represent and magnify their voices.

I am proud of all of the work that LUNGeivity is doing to improve outcomes for people diagnosed with lung cancer, and I applaud all of the people who are demanding change.

Together we can create a world where no one dies of lung cancer.

To learn more about how you can get involved, visit www.LUNGeivity.org

Andrea E. Ferris

LUNGEVITY'S MISSION

LUNGeivity Foundation is firmly committed to making an immediate impact on increasing quality of life and survivorship of people with lung cancer by accelerating research into early detection and more effective treatments, as well as by providing community, support, and education for all those affected by the disease.

THE IMPORTANCE OF BIOMARKER TESTING

LUNGeivity's Take Aim Initiative

Personalized medicine is more important than ever with the identification of new biomarkers, improved testing methods to detect known biomarkers, and the rapidly evolving landscape of lung cancer therapy.

LUNGeivity is a strong advocate for personalized medicine and in 2015 created the Take Aim initiative to ensure that patients have access to biomarker testing to help guide their treatment decisions in a timely way. Biomarker testing is an important part of a lung cancer diagnosis as it may provide information about changes, or mutations, in cells that became cancer, and specific treatments may be available to target these changes. Despite the benefits, many patients are still not tested, and Take Aim's goal is to ensure *all* patients are tested.

Since the initiative began, LUNGeivity has made positive strides forward in breaking down barriers to patient access to biomarker testing. *continued on page 11*

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Tom Galli, Michael Marquis, and Andre Owens Join LUNGevity Foundation Board of Directors

LUNGevity is pleased to announce three recent additions to the Board of Directors. Tom Galli, Michael Marquis, and Andre Owens, working together with other global leaders on the Board, will lend their expertise and passion to further LUNGevity's work of changing outcomes for people with lung cancer through research, education, support, and vital public policy work. Tom is a lung cancer survivor, while Michael and Andre have lost loved ones to lung cancer; they bring a strong personal motivation to increasing survivorship in lung cancer.



Tom Galli is a 14-year lung cancer survivor, a retired Lieutenant Colonel of the United States Army, and the founder of patent holder company Ingenium Cubed,

L.L.C. Tom's career in the United States Army and the corporate world spans 45 years and includes a diverse background in civil engineering; tank-automotive system design, development, and manufacturing; contracting; program management; and productivity and business process re-engineering consulting. Commissioned in the Army Corps of Engineers in 1972 after graduation from University of Dayton, Tom's military career began with troops in a Combat Engineer Battalion, included managing and directing the Army's Abrams Tank production contracts and plants and leading initial production manufacturing of the M-9 Armored Combat Earthmover. After Army retirement, Tom founded Ethell-Galli Consulting International, a civil works and management services consulting firm. He joined Raytheon-E Systems in 1997 where, as Director of Advanced Concepts, he focused on

marrying emerging technology with customer needs, gaining a promotion to Six Sigma Director and Champion in 2000. Tom founded Ingenium Cubed L.L.C., a patent holding company. He holds three patents, is a published author, earned an MBA, and is a graduate of the Defense Systems Management College, the Defense Contract Audit Agency Institute, and the Armed Forces Staff College.

Michael Marquis was appointed President of Vogue International, a Johnson & Johnson Company, in 2016, and tasked with completing a seamless merger into



J&J while plotting a path for Vogue's growth. As a valued member of the North American Leadership Team at J&J, he works in partnership with the other consumer brands to contribute to the advancement of human health in conjunction with the Credo of Johnson & Johnson. In 2014, Michael took on the leadership of the portfolio of businesses including iconic brands LISTERINE® and BAND-AID®. By focusing on core priorities and establishing a culture of

health and learning, he was able to grow market shares of key product lines and build a team of leaders for the future. Prior to that, Michael was responsible for the Global Oral Care Franchise at J&J, where he headed up global strategy, marketing, innovation, and business development into emerging markets. Michael graduated from Bucknell University with a bachelor's degree in accounting.

Andre Owens is a partner in the Washington, DC, law office of WilmerHale. His legal practice focuses on securities trading and markets activities. He coun-



sels broker-dealers, securities exchanges, investment advisers, and other clients on a variety of regulatory issues. In the past, Andre served as a member of the U.S. Securities and Exchange Commission's Office of General Counsel. He also served as counsel to former SEC Commissioner Steven M. H. Wallman. Andre graduated from Providence College with a bachelor's degree and holds a JD degree from Harvard Law School.

"We are excited and honored that Tom, Michael, and Andre have joined our board. They each bring specialized knowledge and perspectives that will support LUNGevity's strategic growth in the coming years."

ANDREA FERRIS

President and CEO, LUNGevity Foundation



1) Andrea Ferris, President and CEO of LUNgevity, with Jill DeSimone, Senior Vice President, US Oncology, Merck, who accepted the 2017 NYC Gala Hope Award for Corporate Leadership on behalf of Merck. **2)** Amanda Kouri, lung cancer advocate and survivor and recipient of the 2017 NYC Gala Face of Hope Award (third from left), with (left-right) lung cancer survivors Patti Helfand, Alisa Brenes, and Barbara Kotler. **3)** 2017 NYC Gala Chair Lynne Doughtie with Gala Vice Chairs Peter Babej (l) and Alex Stern (r). **4)** Discoing the night away at the 2018 DC Gala. **5)** 2018 DC Gala guests bidding support for The SU2C-LUNgevity Foundation-American Lung Association Lung Cancer Interception Dream Team research project. **6)** 2018 DC Gala Chairs Larry Aschenbach and Greta Kreuz welcome guests. **7)** 8th National HOPE Summit attendees in one place!

Two Evenings and One Weekend Inspire the Lung Cancer Community

Two spectacular galas, the 5th annual Celebration of Hope Gala in NYC in November 2017 and the 7th annual Musical Celebration of Hope Gala in Washington, DC, in April 2018, attracted leaders of business, philanthropy, and science to raise funds for LUNgevity research, education, and support programs;

honor those individual and organizations whose commitment and efforts to improve outcomes for lung cancer patients are making a difference; and just plain have a good time celebrating all the progress being made through lung cancer research. Honorees at the 2017 NYC Gala included Merck (Hope Award

for Corporate Leadership) and Amanda Kouri, a young lung cancer advocate and survivor as well as the face of the Inhale for Life campaign (Face of Hope Award). Honorees at the 2018 DC Gala included the U.S. Department of Veterans Affairs (Public Service Face of Hope Award), Foundation Medicine (Hope Award for Corporate Leadership), and Philip Bonomi, MD (Face of Hope Award).

The 8th National HOPE Summit brought together hundreds of lung cancer survivors, caregivers, and advocates, who spent several April 2018 days in Washington, DC, at educational sessions — for lung cancer survivors, caregivers, and advocates — and social gatherings. Attendees went home with new knowledge and skills along with lasting connections of friendship and support.



advances

Getting Ahead of Inherited Lung Cancer



Zeynep H. Gümüş, PhD

Many people with family histories of cancer are getting tested to identify their cancer risk and take action before it starts. For example, the actress Angelina Jolie, who inherited the BRCA1 gene and whose mother died of ovarian cancer, underwent two preventive surgeries to reduce her risk of breast and ovarian cancer, while patients with an increased risk of colon cancer often take a daily dose of aspirin to reduce their risk.

LUNGeivity awardee Zeynep H. Gümüş, PhD, Assistant Professor of Genetic and Genomic Sciences at the Icahn School of Medicine at Mount Sinai and an expert in using computational technology to analyze the biology of cancer cells, wanted families with a history of lung cancer to be able to reduce their risk, too.

“I was inspired by the progress in other cancers,” says Dr. Gümüş, “and I wanted to help the families of lung cancer patients by developing tests that would tell them if they are at increased risk of lung cancer.”

Identifying patients who are at high risk for lung cancer would mean they could be screened more frequently and the cancer could be detected earlier. Finding lung cancer early, in stage I or II, significantly increases survival.

Researchers have already been looking for genetic variants that predispose someone to lung cancer. So far, they have been using computing power to search through common variants. They have found some variants that could possibly demonstrate a predisposition to lung cancer in approximately 2% of the lung cancer population.

“The previous work is not enough to use to develop a risk assessment test for lung cancer,” explains Dr. Gümüş. “We need to look for *rare* genetic variations. Each person normally has about 100-150 rare variants. We need to compare them and see if we can find one or more variants that predispose someone to getting lung cancer.”

At Mount Sinai, Dr. Gümüş has a lot of computational power at her fingertips. “Our high-performance computing clusters are world-class. We have the storage capacity and computational power to look for these rare genetic variants in hundreds of people in a reasonable amount of time.”

Dr. Gümüş first took advantage of this computational powerhouse to make major breakthroughs in identifying genetic variants that drive cancer progression. Then, in 2014, she was ready to do the same for variants that predispose individuals to non-small cell lung cancer, so she assembled a team of expert collaborators and applied for a research grant from LUNGeivity Foundation.

The LUNGeivity grant, along with the team’s expertise and the tremendous computing power at Mount Sinai, allowed Dr. Gümüş and her team to study the rare genetic variations in a population of Ashkenazi Jews. By focusing on the genetics of this group, which has less genetic diversity than the general population, the team was able to reduce background noise and find the rare variants they needed. Ultimately, Dr. Gümüş and her team identified a set of genes that indicates an increased risk of non-small cell lung cancer.

Dr. Gümüş expects that her collaborators will move forward with these findings to develop a unique biomarker signature test that tells patients if their family members are at increased risk of lung cancer. “Family members will simply give spit or blood to the lab for testing,” she says. “More work is needed, just to confirm that this test is worth people’s time. But based on our results, this panel of tests is very exciting.”

Encouraged by these results, Dr. Gümüş is applying for federal funding to continue her work. This time, she wants to look for genetic variations that predispose families to small cell lung cancer.

“This wouldn’t have been possible without the Early Detection Award from LUNGeivity,” notes Dr. Gümüş. “Because of the award, I have learned so much about lung cancer detection and treatment. Plus, I am now part of an amazing network of lung cancer researchers that continues bringing hope and progress to lung cancer patients and their families.”

Highlights of AACR 2018

DRIVING INNOVATIVE CANCER SCIENCE TO PATIENT CARE

by Upal Basu Roy, PhD, Director of Translational Research and Director of Patient FoRCe

The title of this article, *Driving Innovative Cancer Science to Patient Care*, was the name of this year's AACR April meeting in Chicago, and it was a fitting name—there were lots of exciting advances in targeted therapies, immunotherapy, and more that I am pleased to share with you here.

Progress in **TARGETED THERAPIES** is continuing in two areas:



John Heymach, MD, PhD

Understanding how to overcome EGFR and

ALK mutations: Currently, patients whose tumors have an EGFR or ALK mutation are treated with drugs called tyrosine kinase inhibitors (TKIs). Although these

drugs work really well initially, the cancer inevitably comes back by developing resistance to them. When a patient progresses on a first- or second-generation EGFR TKI, they are typically prescribed a third-generation TKI called osimertinib (Tagrisso®). This drug works by blocking a mutation called T790M, which cancer cells develop to outsmart the initial EGFR TKI(s) used. However, cancer cells have now developed mechanisms to resist osimertinib as well. Work from LUNGevity SAB Board member **Dr. John Heymach's** laboratory shows that EGFR-positive lung cancer cells develop resistance to osimertinib via additional mutations in the EGFR gene—such as C797S or L792H—or they may lose the T790M mutation that makes them sensitive to osimertinib. This research is setting the foundation for answering *What's next?* for patients whose cancer comes back after osimertinib treatment.



Alice Shaw, MD, PhD

Patients whose tumors are positive for the ALK gene rearrangement also relapse after treatment with ALK TKIs because their lung tumors develop additional mutations in the ALK gene.

LUNGevity SAB member **Dr. Alice Shaw's** laboratory showed that such patients may respond to a third-generation ALK TKI, lorlatinib. Lorlatinib has the potential to

become an option for ALK-positive lung cancer patients in the not-too-distant future; the FDA has given it priority review status.

Targeting mutations such as KRAS—previously considered untreatable—and

other, rare mutations: Progress is being made in targeting genes such as KRAS, long considered “undruggable.” Scientists have already developed drugs that block G12C, a specific mutation in the KRAS gene, the most common mutation in lung cancer. These drugs have shown immense promise in preclinical studies, and we hope to see them move into clinical trials by the end of the year. In addition, scientists have started developing drugs for other types of KRAS mutations and testing these in preclinical studies.

We may soon have drugs that block the RET mutation, found in only 1%-2% of non-small cell lung cancer (NSCLC) patients. Data from a Phase 1 trial with a RET-blocking drug show that the drugs worked in 50% of the patients enrolled in the clinical trial. Although the trial included only a small number of patients, the data are promising and will lead to Phase 2/3 trials soon.

IMMUNOTHERAPY, specifically “rational immunotherapy combinations,” might have made the biggest splash at this year's AACR. Scientists are learning how to combine and sequence immunotherapy drugs with other immunotherapies or with conventional treatments such as chemotherapy. Data from a Phase 3 combination trial using an immune checkpoint inhibitor called pembrolizumab (Keytruda®) in combination with chemotherapy (pemetrexed-platinum compound) showed that the combination was far superior to chemotherapy alone in the first-line setting for advanced-stage non-squamous NSCLC, a subset of NSCLC. The most interesting piece of the

data was that this effect was seen independent of PD-L1 protein expression. PD-L1 is a biomarker often used to identify which patients may respond to immunotherapy. In addition, another trial studying a combination of two immune checkpoint inhibitors, ipilimumab (Yervoy®) and nivolumab (Opdivo®), showed that the combination was more effective than chemotherapy alone in the first-line setting for advanced-stage NSCLC patients. Additional data from this trial are awaited. Immunotherapy is also showing promise in early-stage lung NSCLC patients. LUNGevity Career Development Awardee **Dr. Patrick Forde's** work showed that immunotherapy given to early-stage NSCLC patients before surgery (also known as neoadjuvant immunotherapy) may prevent the cancer from recurring after surgery. This trial has laid the groundwork for several neoadjuvant immunotherapy trials for early-stage NSCLC patients. [Read more about Dr. Forde's work on page 7.](#)



Patrick Forde, MB, BCh

Research in **SMALL CELL LUNG CANCER**

(SCLC), which has not yet seen the progress in treatments that NSCLC has, has definitely taken off. The small-cell session chaired by LUNGevity awardee **Dr. Julien Sage** focused on the latest research on understanding how SCLC lung cancer cells become resistant to chemotherapy and whether combination treatment approaches for SCLC are effective. DLL3, a protein produced in excess by SCLC cells, continues to progress through clinical development, not just as a therapeutic target, but also as a possible imaging target for SCLC. LUNGevity's Scientific Advisory Board



Julien Sage, PhD



Charles Rudin, MD, PhD



Lauren Byers, MD

chair, **Dr. Charles Rudin**, presented promising data on how SCLC evades the effects of chemotherapy by stopping the production of a protein called SLFN11. Combining chemotherapy with drugs that restore the production of SLFN11 makes SCLC sensitive to chemotherapy in preclinical studies. Clinical trials testing these combinations are expected to start soon.

LUNgevity Career Development Awardee **Dr. Lauren Byers'** team showed that SLFN11 may also be a biomarker for response to PARP-blocking drugs. PARP inhibitors are currently in clinical trials for SCLC, and SLFN11 may serve as a potential biomarker to predict which patients will derive benefit from these drugs. Her team also presented data that showed

that combining immunotherapy with drugs that block a protein called CHK1 may work better in SCLC cells than immunotherapy alone.

No cancer conference is now complete without sessions on **LIQUID BIOPSIES**. Although liquid biopsies are not quite ready for prime time, considerable progress has been made in the new technology that relies on testing blood from lung cancer patients. Circulating tumor cells, or CTCs, are cancer cells shed by certain types of tumors into the blood. Detection of CTCs in the blood of **early-stage** cancer patients suggests a more aggressive cancer. Scientists are refining CTC-based technologies to better identify early-stage NSCLC patients who will have a higher chance of recurrence after surgery. CTC-based technology is also being developed for SCLC to classify which late-stage SCLC patients will not respond to chemotherapy and so may need to be monitored more vigilantly.

In her opening plenary presentation, **Dr. Margaret Foti**, the Chief Executive Officer of the AACR, recognized the importance of **PATIENT ADVOCACY GROUPS** in increasing awareness about cancer, helping raise funds for research, and partnering with researchers to develop drugs and execute clinical trials. A perfect example is the work of the ROS1ders, a group of passionate ROS1-positive lung cancer survivors and their caregivers, which was presented at a poster session. This group is building a global community to accelerate ROS1 research and turn ROS1+ cancer into a manageable chronic disease.

This AACR meeting was just one of the important annual meetings where lung cancer research is presented. Next up, in June, is the American Society of Clinical Oncology (ASCO) conference. News from that conference will be presented in the Fall 2018 newsletter.

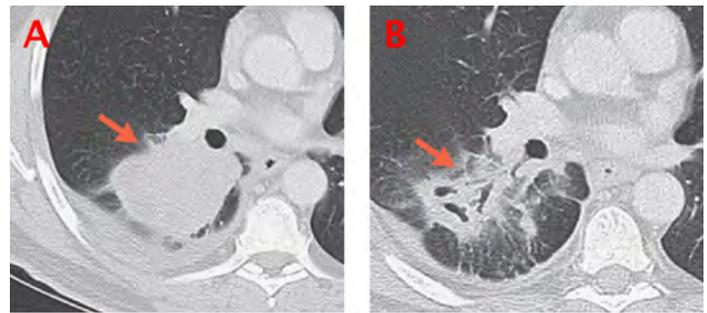
Immunotherapy Given Before Surgery May Help Early-Stage Lung Cancer Patients

Immune checkpoint inhibitors—a new class of immunotherapy drugs—have shown promise in advanced-stage non-small cell lung cancer (NSCLC). Cancer cells escape from the immune system by producing proteins that dampen the immune response. Immune checkpoint inhibitors restore the immune system's ability to track and kill cancer cells. Currently, immune checkpoint inhibitors are used to treat advanced-stage NSCLC.

Early-stage NSCLC patients (stages I, II, and IIIA) are typically treated with surgery. However, surgery is often not curative and the cancer comes back in about 50% of these patients.

A recent clinical trial led by Dr. Patrick Forde from the Kimmel Cancer Center at the Johns Hopkins University School of Medicine suggests that checkpoint inhibitors may help in treating early-stage NSCLC patients. The study, supported by a 2014 LUNgevity Career Development Award, demonstrated that an immune checkpoint inhibitor called nivolumab (Opdivo®), given before surgery in early-stage patients, may delay recurrence. In the small clinical trial of 20 patients who received nivolumab before their surgery, 16 of the patients remained cancer-free 12 months after their surgery. When tumors from these patients were tested, the research team found that the tumors were filled with tumor-fighting immune cells called T-cells. These T-cells were also found in blood samples of the patients.

Dr. Forde's study suggests that use of immunotherapy in early-stage cancer patients before surgery (also known as



Neoadjuvant immunotherapy in early-stage non-small cell lung cancer: Computerized tomography (CT) scan of stage IIB patient before (A) and after (B) immunotherapy before undergoing surgery. Red arrow identifies the tumor before and after immunotherapy, before the patient underwent surgery.

neo-adjuvant immunotherapy) may help generate tumor-fighting T-cells that persist in the blood and fight any residual cancer cells. Several Phase 3 clinical trials with larger numbers of patients are currently underway.

This practice-changing research was published in the prestigious *New England Journal of Medicine* on April 16, 2018, and presented at a platform presentation at the annual American Association for Cancer Research meeting in Chicago in April.

Figure courtesy of Dr. Patrick Forde, Johns Hopkins University School of Medicine

Reference: Neoadjuvant PD-1 Blockade in Resectable Lung Cancer.- Forde PM et al. N Engl J Med. 2018 Apr 16. doi: 10.1056/NEJMoa1716078.

Driving Reform in Clinical Trials

LUNGeVity convened our third annual Scientific and Clinical Roundtable on Clinical Trials in the fall to continue to drive change in the way clinical trials are developed and conducted. The meeting, attended by Dr. Rick Pazdur, Director of the FDA's Oncology Center of Excellence, and his team, furthered work on the three main work streams: expanding eligibility criteria in order for more patients to have access to trials; streamlining reports of adverse event reporting so less time is spent on paperwork and processing; and evaluating opportunities for a synthetic control arm, which would allow more patients in trials to have the new therapy rather than standard of care.

This was the first time that the EMA, the European counterpart of the FDA, participated. EMA's participation and perspective at the meeting was groundbreaking and made evident that the reform LUNGeVity is driving has gone global. The meeting also included stakeholders from industry, academia and government, and patient representatives.

LUNGeVity's Scientific and Clinical Roundtables expanded in 2018 to include our first Scientific and Clinical Roundtable focused on Patient Reported Outcomes (PROs). This multi-stakeholder meeting included Theresa Mullin, FDA's Center for Drug Evaluation and Research (CDER) Associate Director for Strategic Initiatives and head of the FDA's Patient-Focused Drug Development (PFDD) initiative, along with her team, industry partners, payors, European health technology assessment agencies (UK NICE), clinicians, and patients. The goal of the meeting was to home in on what should be measured with PRO instruments (what is important to patients), how to measure PROs, and how to communicate the results of the surveys. Through the Scientific and Clinical Roundtables, LUNGeVity is driving the process of engaging patients as true partners in clinical development. LUNGeVity is proud to continue our commitment to patient centricity and to advocate for the continued incorporation of the patient perspective in all aspects of cancer care.

Enhancing Veteran Access to Clinical Trials

continued from page 1

Through a two-fold initiative of 1) facilitating options for referring veterans out of the VA to participate in clinical trials at academic institutions and 2) supporting long-term goals set by the VHA to create more trials within the VA system, we are hoping to make immediate and lasting change for veterans. LUNGeVity is working with the VA Office of Research &

Development (ORD) to accomplish these goals through one-on-one meetings with the administration and co-sponsorship of multi-stakeholder roundtables. The first roundtable was held on April 12, 2018, and included attendees from the VA ORD, clinicians, researchers, administrators, and industry partners to identify and start to address barriers to setting up clinical trials in the VHA. We are also working with veteran service organizations, advocacy partners, and members of Congress to accelerate this progress.

Great strides have been made on both focuses of the initiative since its launch in summer 2017, and we expect even more progress in 2018. If you would like to learn more about this initiative or speak with our team about ways that you can be involved, please reach out to Meriam Driss, Senior Director of Strategic Partnerships, at mdriss@LUNGeVity.org or to Anna Pugh, Director of Public Policy Initiatives, at agpugh@LUNGeVity.org.



Charity Navigator, the nation's most trusted charity evaluator, has awarded LUNGeVity a second consecutive 4-star rating, earned only by charities with the highest levels of transparency, reliability, and fiscal responsibility. In fact, only 30% of the charities evaluated by Charity Navigator have received at least two consecutive 4-star evaluations.

LUNGeVity Foundation continues to be a conscientious steward of your contributions.

Get help navigating your lung cancer diagnosis

- **Information** about lung cancer and treatment options
- **Personalized support** and counseling
- **Referrals** to financial assistance resources for needs including pain medication, homecare, childcare, medical supplies, transportation for treatment, and copayment assistance

Call the toll-free Lung Cancer HELPLine at 844-360-LUNG (5864), 9:00 a.m.- 5:00 p.m. Eastern Time, Monday through Friday

Upstage Lung Cancer

CELEBRATING 10 MUSICAL YEARS OF ADVOCACY AND RESEARCH FUNDING



Hildy Grossman (fourth from left) and cast of an Upstage Lung Cancer show to benefit lung cancer research

An interview with Hildy Grossman, founder of Upstage Lung Cancer and an 11-year lung cancer survivor.

Q: Hildy, what is your personal lung cancer story?

Hildy: Lung cancer can happen to anyone. It's random — I figure if it happened to me, it could happen to anyone. I'm healthy, active, and a non-smoker. I was diagnosed in November 2006, completely by accident, when I slipped on my stairs with a new pair of shoes. After an MRI and mishap diagnoses and referrals, I was lucky to find the lung cancer at the earliest stage.

Q: Upstage Lung Cancer has a unique approach to raising awareness. What was your inspiration?

Hildy: I needed to get the word out that if you find lung cancer early, survival rates increase and lives are spared. I thought: I've never run an organization, but I'm a singer and I do know how to produce a wonderful concert. With the help of friends, one

a fellow lung cancer survivor, we created the only organization that exclusively uses music and the performing arts to raise awareness and funding for early-detection lung cancer research. This is the 10th anniversary of our founding!

Q: Upstage Lung Cancer has been partnering with LUNgevity to fund research since 2012. What makes it work?

Hildy: I knew so little when I was first introduced to LUNgevity. Through our partnership, we were able to benefit from LUNgevity's outreach capabilities and invest in world-class research. I was most impressed and grateful that Upstage Lung Cancer was given the opportunity to choose to support research from among the projects LUNgevity had targeted for funding. Having a voice in supporting research that best reflects our mission has been the hallmark of a valuable partnership between a small and a large lung cancer patient advocate organization. Together, we've funded several exciting early

detection studies, including the second year of the research of Dr. Lida Hariri of Massachusetts General Hospital. She is using a new optics technique to create tools to guide tissue biopsies for better sampling and a more accurate diagnosis.

Q: What impact do you hope Upstage Lung Cancer will have?

Hildy: Most people in the general population don't want to talk or hear about lung cancer. It is still a disease with stigma. My hope is that the joy of music can be the pied piper leading people to listen and learn about the progress and hope that continue to grow for lung cancer patients. We have found that at the end of a concert, our audience has had a wonderful time and feels more aware of the current need for more research to save lives. As Gershwin said, "Who could ask for anything more?"

SAVE THE DATE!

October 23, 2018

Upstage Lung Cancer presents

Barbra, Bette & Bernadette: Women Show-Stoppers

.....
an evening of song, with Emmy-Award-winning Emcee and performed by the best of Boston's professional actors and musicians. The show will mark 10 years of funding early detection lung cancer research and will benefit LUNgevity Foundation.

Mosesian Center for the Arts
321 Arsenal Street • Suite 2
Watertown, MA 02472

Thank you to survivors, volunteers, friends, and family for participating in Fall 2017 Breathe Deep and Team LUNGevity events. You make the lung cancer community stronger! Be sure to check out our 2018 events.



2017 Breathe Deep events pictured here

- 1) Naperville, IL
- 2) Baltimore, MD
- 3) Team LUNGevity-Chicago, IL
- 4) Amador, CA
- 5) Busse Woods, IL
- 6) Boca Raton, FL
- 7) Ft. Myers, FL
- 8) Nashville, TN
- 9) Phoenix, AZ
- 10) Liverpool, NY
- 11) Washington, DC
- 12) Philadelphia, PA

Chicago, Chicago!

LUNgevity is a national organization, but did you know its roots are in the Chicago area?



Patti Helfand

LUNgevity Foundation was founded in 2001 by seven people who had each been diagnosed with lung cancer. It was their vision and passion for finding a cure that resulted in LUNgevity's phenomenal growth. In starting a small Chicago-born organization and nurturing it to become the nation's fastest-growing charity in less than ten years, these very special people left an indelible legacy. Patti Helfand, of Chicago's North Shore, is the sole remaining member of the original seven founders.

Today, the Chicago area is home to some of LUNgevity's strongest supporters. The area hosts a variety of LUNgevity events, from Breathe Deep North Shore, now just finishing its seventh year, to the Chicago HOPE Summit. The Windy City and its neighboring towns come out in force to raise awareness and funds for lung cancer research.

"The North Shore lung cancer community continues to grow — at our Breathe Deep 5K fun run and walk on May 6, we had close to 900 participants," reported Lisa Spathis, Breathe Deep North Shore event co-coordinator. "Donations are still coming in, and we hope to raise \$220,000."

On May 10, LUNgevity Foundation hosted **LOL ... to Beat Lung Cancer** — an evening of laughter at The Second City's UP Comedy Club Theatre. There was a pre-show reception and "Legendary Laughs" — a 90-minute revue featuring the best of The Second City.

"The evening was an opportunity for the Chicago community to join together to help change the outcomes for people with lung cancer," said event chair and LUNgevity Board member Marc Swerdlow. "We knew that laughter would bring people together in an unexpected way while raising funds for research and support."

Area residents can also take advantage of the upcoming regional HOPE Summit, a day of expert speakers, tips on living well with lung cancer, and opportunities to share with other survivors and caregivers. For more information about the Chicago HOPE Summit on October 6, 2018, visit www.lungevity.org/hopesummits.

Are you an endurance athlete? Raise money for LUNgevity while running the Bank of America Chicago Marathon and Chicago Half Marathon by joining Team LUNgevity. Learn more at www.lungevity.org/teamlungevity.

Andrea Ferris, President of LUNgevity, stressed, "We are grateful for the role that the greater Chicago community has played, and continues to play, in the organization's growth and efforts to create a world where no one dies of lung cancer."

"I am so proud to be a part of LUNgevity. From our grassroots beginning in the suburbs of Chicago to a national organization, we are exceeding the goals of the founders. Our continuing efforts, through research and support, give us hope—hope that our vision of a world where no one dies of lung cancer will be a reality."

PATTI HELFAND

LUNgevity's Take Aim Initiative

continued from page 2

LUNgevity has worked with relevant stakeholders, from pulmonologists and pathologists, who acquire and test the tissue, to pharmaceutical companies, professional societies, clinicians, and other patient advocacy groups. LUNgevity is also working with policy makers to (1) break down barriers caused by regulatory issues such as delay in testing due to reimbursement policies, (2) advance the adoption of next-generation sequencing and (3) develop oversight of diagnostic tests to ensure quality.

Access is just one key piece to the

biomarker paradigm, however; awareness and education are also a huge piece of Take Aim to ensure patients (and their physicians) both know and understand the importance of testing. In Spring 2017, LUNgevity conducted a Messaging Audit of marketing and education materials of pharmaceutical and patient advocacy groups, as these groups are most likely to create education materials; the audit focused on key message points to determine if consistent messaging is possible. In March 2018, the audit was presented at the CancerCare Biomarker Roundtable and became the framework of discussion and the basis for consensus building on what information should be included in testing

education materials. LUNgevity is working with Cancer Support Community to draft guidelines for biomarker education materials for other organizations to follow. This concordance will help ensure that education materials are consistent, concise, and comprehensive, hopefully raising awareness and understanding of testing.

These are just some of the many accomplishments achieved as part of Take Aim since its inception. LUNgevity will continue its work advocating for biomarker testing, next focusing specifically on tissue acquisition and handling to ensure proper tissue is gathered and tested for best results for patients.



228 South Wabash Avenue, Suite 700
Chicago, IL 60604
312.407.6100

JOIN US AT THESE FUN AND INSPIRING LUNGevity SPRING AND SUMMER EVENTS

June 2	Breathe Deep Michigan	Birmingham, MI
June 2	Breathe Deep Move to the Groove Concert	Blue Ridge, GA
June 2	Breathe Deep South Lyon	South Lyon, MI
June 10	Breathe Deep Toledo	Toledo, OH
June 24	Breathe Deep NEPA	Kingston, PA
August 11	Breathe Deep Salt Lake City	Salt Lake City, UT
August 18	Breathe Deep Seattle	Seattle, WA
August 25	Breathe Deep John Whiteside/Beatrice Green Lung Cancer Walk	Arlington Heights, IL
August 26	Transamerica Chicago Triathlon (Team LUNGevity)	Chicago, IL
September 9	Breathe Deep DuPage	Naperville, IL

For additional information about events near you, visit www.LUNGevity.org/events



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