

# fresh air

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## ANNOUNCING

# The International Lung Cancer Survivorship Conference

Building on the success of the LUNGeVity HOPE Summit, a summit dedicated to survivorship and teaching people how to live well with lung cancer, LUNGeVity is launching the International Lung Cancer Survivorship Conference (ILCSC).

ILCSC, a unique, global conference, will be composed of three simultaneous summits: the HOPE Summit for patients, the COPE Summit for caregivers, and the Survivor-

ship Summit for advocates and survivors who are interested in more advanced topics. Participants will be able to pick [continued on page 2](#)



## LUNGeVity Presents at the World Conference on Lung Cancer

The results of four studies completed through Patient FoRCe, LUNGeVity's patient-focused research institute, were presented at the International Association for the Study of Lung Cancer's 19th World Conference on Lung Cancer, in Toronto, Canada, in September 2018. This conference is the world's largest devoted to lung cancer and other thoracic malignancies. [continued on page 11](#)

REFLECTIONS FROM  
THE DESK OF THE  
PRESIDENT AND CEO



*November is Lung Cancer Awareness Month, when we raise awareness of the facts about lung cancer and celebrate the real progress that is being made for patients. In recent years, research in lung cancer has led to earlier detection and better patient outcomes. We're proud to help drive this progress.*

*LUNGeVity continues to advance impactful, scientific research, from the first-ever projects funded by the patient advocacy group ALK Positive to those of LUNGeVity's newest cohort of Career Development Awardees.*

*Our Patient-Focused Research Center (Patient FoRCe), launched 18 months ago, continues to study the lived experience of people diagnosed with lung cancer through qualitative and quantitative research projects. Learn about the great work accomplished in the last year and a half, including presenting studies at world conferences.*

*Finally, this year's national HOPE Summit brought together close to 400 survivors, caregivers, and healthcare professionals. You'll want to read about how we've expanded this unique international survivorship conference for 2019 to be even bigger and better.*

*To learn more about Lung Cancer Awareness Month, visit [www.LUNGeVity.org](http://www.LUNGeVity.org). We thank you for your support.*

Andrea E. Ferris

#### LUNGEVITY'S MISSION

**LUNGeVity 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.**

#### ILCSC, *continued from page 1*

and choose from sessions at any of the three summits based on their specific needs and lung cancer knowledge base.

ILCSC will also include an expanded exhibit hall, which will feature booths with information from industry, other patient advocacy organizations, and resources for patients, caregivers, and their families.

Like the HOPE Summit, ILCSC will be a highly supportive conference in which participants hear from experts on the latest in lung cancer research and clinical practice, learn from and empower each other, and develop a new support

network, having forged connections with peers from around the globe who have been affected by a lung cancer diagnosis.

"The HOPE Summit has been a life-changing event for so many of the participants," said Andrea Ferris, President and CEO of LUNGeVity. "We are thrilled to be able to expand its reach through this conference and address even more issues people diagnosed with lung cancer face."

**We hope you will join us in Washington, DC, April 26-28, 2019, for this life-changing event!**

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## LUNGEVITY LAUNCHES INHALE FOR LIFE:

# New Biomarker Testing Campaign

LUNGeVity is launching a new social media and PSA campaign to encourage people diagnosed with non-small cell lung cancer (NSCLC) to ask their doctor about biomarker testing at the time of diagnosis or recurrence.

As a follow-up to our successful #Inhale-ForLife campaign, we will share five stories of survivors who have benefited from this testing—five individuals who are taking targeted therapies and are leading their lives. The survivors are opening new businesses, raising young families, running marathons, and traveling with their loved ones. They epitomize the hope of new treatments for lung cancer patients.

Lung cancer treatment options now include a number of targeted therapies aimed at particular driver mutations and several immunotherapies aimed at enhancing a person's own immune system. Each of these treatments can provide substantial benefits—but not to all patients.

For doctors to know whether to prescribe any of these treatments to a lung cancer patient requires biomarker testing. Biomarker testing is used to determine the presence of particular mutations or of a particular protein, how aggressive the disease is, and whether a patient is likely to respond to a particular treatment. It is the first step in precision medicine—ensuring that a patient gets matched to the right treatment at the right time, based



WATCH the video. LEARN the facts.  
GET tested.

*Quintano Downes, lung cancer survivor, and his son take a stroll in the new Inhale for Life: Biomarker Testing Campaign video, a PSA campaign to encourage people diagnosed with NSCLC to get biomarker tested.*

on the patient's biomarker profile. However, not all patients who could benefit from targeted therapies are undergoing biomarker testing.

This campaign is part of LUNGeVity's broader efforts, including Take Aim, in promoting precision medicine in lung cancer. Look for our videos on Facebook, Instagram, and Twitter starting in November for Lung Cancer Awareness Month. Please share with your network and help us raise the rate of biomarker testing for patients with NSCLC.

## Making Patient-Reported Outcomes More Patient-Centric

Patient-Reported Outcomes, or PROs for short, are a part of life for a lung cancer patient while on a clinical trial. PROs are status updates on side effects, functionality, quality of life, or other disease-related conditions that come directly from the patient, rather than through a doctor, to ensure patients' perspectives are heard and understood.

While many patients are familiar with PROs, most do not know how researchers actually use these results, as LUNGeVity learned at a meeting during this year's HOPE Summit. At the summit, a group of patient attendees met with members of

the FDA who focus on PROs to discuss their perspective on PROs and how they are used. While the FDA was interested in learning what patients felt were important considerations in making treatment decisions, it became clear throughout the discussion that patients were under the impression that their PROs were being used to determine whether or not they would remain on a clinical trial rather than to inform treatment decisions for future patients. This misunderstanding leads to a lot of underreporting of side effects by patients.

*continued on page 11*

## November is Lung Cancer Awareness Month

November is Lung Cancer Awareness Month, a time to educate the public about the disease and share stories of lung cancer patients, survivors, and their families. LUNGeVity is spreading the word, and YOU can make a difference.

### SHOW YOUR SOCIAL MEDIA SAVVY!

Let your point of view be known with a Facebook video using the new LUNGeVity LungCam. It's a great way to personalize your message. It's easy to do, and we're asking new questions on key issues every week! Share LUNGeVity posts with your network to spread the message, post a photo with one of our downloadable lung cancer facts to Facebook, Instagram, Pinterest, and Twitter, or use hashtags when posting, like #LUNGeVity and #changelc.

**TAKE A WALK!** Volunteer for or attend a Breathe Deep event near you. Join survivors, caregivers, friends, and family to celebrate people living with lung cancer and raise funds for LUNGeVity programs.

### LEND A HAND(OUT)!

Distribute LUNGeVity materials to your local hospital or clinic. You'll be helping people find resources and support for their lung cancer journey.

**GET SMART!** Read LUNGeVity online blogs, sign up for our newsletters on our homepage, and check out the website for updates and important information for patients and caregivers.

**There are so many ways to be an advocate this month. Find out more at [www.LUNGeVity.org](http://www.LUNGeVity.org).**

# Most Lung Cancer Survivors Ever in One Place!

This year's National HOPE Summit, now in its eighth year, was our best yet. In April 2018, lung cancer survivors and their caregivers came together in Washington, DC, for the largest gathering of lung cancer survivors to date. LUNGeity welcomed close to 400 participants, who came from many different regions of the country as well as the Philippines and Canada.

Highlights of this year's summit included a keynote address at the Advocacy meeting by Adam Klein, winner of the 33rd season of the reality show *Survivor*, who lost his mother to lung cancer the day he returned home from the show, and the HOPE Summit keynote address by Stand Up To Cancer's President and CEO, Sung Poblete. Expert speakers included Dr. David Schrupp from the National Cancer Institute (NCI), Dr. Jared Surgeon from the

Center for Proton Therapy, Dr. Jose Pacheco from the University of Colorado, Dr. Zofia Piotrowska from Massachusetts General Hospital/Harvard, and Andrew Esch from the Center to Advance Palliative Care.

Educational sessions covered topics including the latest in research (in particular, precision medicine and immunotherapy); clinical trials; quality care; living with lung cancer; nutrition; palliative care; sharing

your story; self-advocacy; and becoming an empowered and informed patient.

At HOPE Summit 2017, one patient, in hospice, stood up and said that her one goal was to live long enough to get to another HOPE Summit. This year, this same patient returned without her oxygen tank and with stable disease. She encouraged others to never give up hope. The impact of HOPE Summit is evident in moments like these.



## Stand Up To Cancer Invites LUNGeity to Telecast

In September 2018, LUNGeity President and CEO Andrea Ferris and many of our HOPE Summit alumni attended the Stand Up To Cancer (SU2C) telecast, celebrating progress in cancer research. The HOPE Summit alumni attendance is the first time the lung cancer community has been prominently represented at a SU2C telecast.

The attendance was a result of the active relationship with SU2C. LUNGeity and the American Lung Association, along with SU2C, collaborated to fund groundbreaking lung cancer research as part of the first-ever Lung Cancer Interception Dream Team and Lung Cancer Translational Research Team.

Sung Poblete, President and CEO of SU2C, was the keynote speaker at the National HOPE Summit in Washington, DC, in April 2018. During her talk, Sung extended invitations to all of the HOPE Summit attendees to participate at the telecast as special guests of SU2C.

LUNGeity is proud of our collaboration with SU2C and the American Lung Association. LUNGeity is leading the way in lung cancer research by forming strong partnerships and driving forward science with the power of collaboration.



### THE INSIDER SCOOP Mary Ann Laverty, HOPE Summit Alum, shares her perspective on attending the telecast

I was introduced to LUNGeity through the National HOPE Summit in Washington, DC, in 2018. While I had wanted to forget about my cancer, attending HOPE Summit made me realize I am part of a bigger community.

Being invited to the SU2C telecast only made the experience sweeter. It was wonderful to see so many HOPE Summit alumni. After a lung cancer diagnosis, you realize how life is intertwined and how we really need each other. We would go up to the other alumni and say, "I remember you!" Being able to connect with others in a similar predicament is so important and meaningful. It makes the feeling of having cancer a lot less lonely.

To me, the stars weren't the Hollywood celebrities but the people in the audience with me, like the man beside me, a newfound friend, who is still fighting cancer, or the person in front of me, who is a survivor. It was amazing to see that there are so many people working and researching for my future, and the future of so many people, and that's the wow moment for me. The only disappointment was I didn't get to see Bradley Cooper. I guess that means I will have to go again next year!

# advances

## HIGHLIGHTS OF WORLD LUNG 2018

# The 3 C's of Lung Cancer

## CHANGE, COLLABORATION, AND CREATION

The 19th World Conference on Lung Cancer (World Lung) in Toronto in September 2018 was the biggest World Lung ever convened—close to 8,000 delegates from 100 countries attended. More importantly, the meeting showcased a number of practice-changing scientific presentations.

**Change is on the horizon:** Practice-changing science pertinent to the entire patient journey, from screening to treatment, was presented. While lung cancer screening using low-dose computed tomography (LDCT) is available in the US to individuals at high risk of developing lung cancer, this is not the case in Europe and other parts of the world. Results from the NELSON trial from Europe presented at the meeting will soon change this. This trial, set up to determine the benefits of LDCT for lung cancer screening, enrolled 15,792 patients and clearly demonstrated the benefit of CT screening to men at high risk for lung cancer, with even more pronounced benefit for women. The study reinforces the population-level benefits of LDCT and also lays the groundwork for additional studies to look at gender differences in lung cancer.

There was also exciting news for ALK-positive lung cancer. A clinical trial with brigatinib, an ALK inhibitor that is currently approved for patients who have progressed on crizotinib, shows that this drug works well in the first-line setting—even for patients who have brain metastases. Soon, ALK-positive lung cancer patients may have a new first-line treatment option.

LUNGeVity Scientific Advisory Board (SAB) member Dr. Scott Antonia presented updated results from the PACIFIC trial testing immunotherapy with chemotherapy and radiation (chemoradiation) for Stage III non-small lung cancer patients (NSCLC). The new results show that adding a checkpoint inhibitor, durvalumab, to chemoradiation provides a clear survival benefit to stage III NSCLC patients. This is big news, given that stage III patients are a unique subset of NSCLC patients with very few treatment options.

Finally, small cell lung cancer (SCLC) may be scoring a big win. Results from the IMpower 133 clinical trial show that the addition of an immunotherapy drug, atezolizumab, to the standard chemotherapy regimen for SCLC is beneficial. The standard of care for SCLC has been chemotherapy for the past 30 years, so this is a big deal.

**Collaboration is the key to change:**

Lung cancer is a complex disease that requires multiple stakeholders to be at the table to come up with solutions. The biggest impact of collaboration was highlighted by the oncogene-driven patient groups, such as the ROS1ders, ALK Positive, EGFRresisters, RET Renegades, and Exon 20 Group. While providing support to patients and caregivers, and increasing awareness about the disease, such patient groups also accelerate research in various ways, including raising funds for research, helping patients enroll in oncogene-specific clinical trials, and providing tissue

and biospecimens for creating new mouse models to study the unique subtype of lung cancer. As LUNGeVity Scientific Advisory Board member Dr. David Carbone pointed out during his plenary talk, “Science that matters!” the first step to developing effective therapies is robust basic science, and development of mouse models to study these unique subtypes of lung cancer is the first phase in testing new drugs.

**Creation of new therapies and treatment paradigms:**

The scientific community has also been hard at work creating new drugs for subsets of lung cancer that are hard to treat. One such subset is lung cancer that has mutations in exon 20 of the EGFR or HER2 genes. These mutations do not respond to the standard EGFR tyrosine kinase inhibitors. Work from SAB member Dr. John Heymach shows that drugs such as poziotinib may be used for these rare subtypes of lung cancer. In addition, scientists are developing new drugs, such as entrectinib and ropotrectinib, for ROS1-positive lung cancer. These drugs are showing promise, both in patients who have been previously treated with crizotinib and those who have never received a ROS1 inhibitor.

LUNGeVity SAB member Dr. Julie Brahmer’s plenary presentation statement “No patient is left behind” is what we, as a community, should be striving for. This year’s World Lung certainly felt like a step in that direction.

# LUNGeivity 2018 Career Development Awards Granted to Three Researchers

LUNGeivity Foundation is proud to grant three recipients its 2018 Career Development Awards (CDA) for lung cancer research: Dr. Kellie Smith, Dr. Jeffrey Thompson, and Dr. Edwin Yau. These awards fund critical lung cancer research projects and offer the recipients world-class mentorship by LUNGeivity's prestigious Scientific Advisory Board.

LUNGeivity Career Development Awards are granted to those early-career researchers whose proposals demonstrate the greatest potential for finding lung cancer at its earliest, most treatable phase, as well as for extending and improving lives of lung cancer survivors. The CDA program encourages their continued development in the field of lung cancer research to grow a strong pipeline of dedicated lung cancer researchers. To date, 10 scientists have graduated from this three-year program.

The 2018 cohort of Career Development Awardees are answering important questions such as,:

- How can we identify which advanced-stage NSCLC patients will benefit from immunotherapy-chemotherapy combination treatment approaches?
- How can we predict which advanced-stage NSCLC patients will respond to immunotherapy with minimum side effects—to deliver the best possible therapy?
- How can we adapt an already existing cutting-edge technology (CRISPR-Cas) to create a blood-based test to complement CT screening for the early detection of lung cancer?

Interestingly, all these projects involve liquid biopsy-based approaches to detecting and optimizing treatment of lung cancer and may define new avenues for applying liquid biopsies in the clinical setting.



**KELLIE SMITH, PHD**

**Johns Hopkins School of Medicine**

**Immunometabolic T cell profiling as a prognostic liquid biopsy in NSCLC**

Checkpoint inhibitors, a type of immunotherapy, are now available in the first-line and second-line settings for certain subsets of NSCLC patients.

*Kellie Smith, PhD*

Furthermore, the US Food and Drug Administration recently approved an immunotherapy-combination treatment regimen for the treatment of a subset of advanced-stage NSCLC patients. While we are making progress in combining and sequencing immunotherapy with other conventional treatments, it is still unclear which patients will respond to these combinations. Dr. Kellie Smith's laboratory is studying immune cells in blood samples from patients who have received the recently approved combination therapy. She postulates that immune cells from patients receiving the combination behave very differently from

immune cells from patients who have received single-agent immunotherapy. Dr. Smith's team will identify and exploit these differences to develop a blood test that will help predict which patients may benefit from combination therapies, thereby sparing patients the exposure to ineffective treatments.



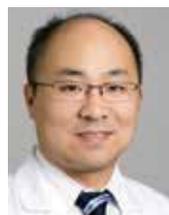
*Jeffrey Thompson, MD*

**JEFFREY THOMPSON, MD**

**University of Pennsylvania**

**Development of markers to predict response to immunotherapy in NSCLC**

Currently, three immune checkpoint inhibitors are approved by the FDA for the treatment of a subset of advanced-stage NSCLC. However, immunotherapy is a costly treatment regimen and comes with a unique side-effect profile because of the inhibitors' ability to cause inflammatory tissue damage. At present, the PD-L1 protein is used as a biomarker to predict which patients may respond to immunotherapy. Unfortunately, presence or absence of the PD-L1 protein may not be an accurate predictor of response. Dr. Jeffrey Thompson is studying how we can develop more accurate biomarker signatures that may not only predict response to immunotherapy, but may also determine which patients will develop treatment-related side effects. He will develop a novel blood-based liquid biopsy approach that will enable doctors to predict which patients will respond to immunotherapy drugs.



*Edwin Yau, MD, PhD*

**EDWIN YAU, MD, PHD**

**Roswell Park Cancer Institute**

**Lung cancer detection by CRISPR-based detection of circulating tumor DNA**

Currently, computed tomography (CT) is available as a tool for the early detection of lung cancer in high-risk individuals. Unfortunately, it has a high false-positive rate: less than 5% of people with nodules found through CT actually have lung cancer. Apart from the distress associated with false positives, individuals may have to undergo a biopsy to rule out lung cancer.

Circulating tumor DNA (ctDNA) is DNA released from dying cancer cells into the bloodstream. Individuals with early-stage lung cancer may have ctDNA in their blood, even when the cancer is localized. CRISPR-Cas technology is a novel DNA modifying tool that can be used to develop sensitive, specific, and economic ctDNA assays. Dr. Edwin Yau will develop a CRISPR-Cas-based blood test to detect ctDNA in the blood of individuals suspected of having lung cancer. While the immediate goal of the project is to evaluate this blood test in individuals who have already undergone a CT scan, the ultimate goal of the project is to develop a blood test for screening all individuals.

# Research Awards Funded by ALK Positive in Partnership with LUNGeivity Foundation

ALK Positive, a group of more than 1,400 ALK-positive lung cancer patients and their caregivers in 41 countries who are raising significant funds for research, and LUNGeivity Foundation have partnered to support high-impact projects that seek to transform the future for patients affected by ALK-positive non-small cell lung cancer. This is the first group of ALK-positive patients to directly influence the direction of research that will, one day, help save their lives.

In May 2018, ALK Positive and LUNGeivity Foundation granted their first set of awards with the monies raised by ALK Positive. Each of these two-year awards is for up to \$200,000. Although the awards are specifically for ALK-positive lung cancer research, they have the potential to benefit lung cancer research in general.

The three projects selected aim to understand how immunotherapy can be used for ALK-positive patients. To date, the success of lung cancer immunotherapy has been restricted to advanced-stage NSCLC patients whose cancers do not have any driver mutations such as ALK. These new projects, which will explore why immunotherapy has not been successful in treating ALK-positive lung cancer and test new immunotherapy approaches in ALK-positive lung cancer, include:



## Characterization of anti-ALK immunologic responses in ALK-positive NSCLC

**Mark Awad, MD, PhD**

*Dana-Farber Cancer Institute*

Dr. Awad's team has discovered that a subset of ALK-positive lung cancers is "immuno-reactive"—patients produce antibodies against the modified ALK protein. However, the role of these antibodies

in the progression of ALK-positive lung cancer is not known. Dr. Awad's team will determine whether patients with antibodies against the modified ALK protein respond differently to ALK tyrosine kinase inhibitors than those patients who do not produce antibodies. His team will next characterize the antibody response to determine which parts of the ALK protein trigger an immune response, with the ultimate goal of producing personalized ALK vaccines.



## Overcoming innate immune resistance in ALK-rearranged lung cancer

**Justin Gainor, MD**

*Massachusetts General Hospital*

ALK-positive lung cancers do not respond to immune checkpoint inhibitors such as PD1 or PD-L1 inhibitors. Dr. Gainor's project aims to understand why these tumors are resistant

to conventional immunotherapy. Are there cancer-cell-specific, tumor-microenvironment-specific, patient-immune-cell-specific

mechanisms, or a combination of these factors that contribute to the lack of response to immunotherapy? His team will identify potential biomarkers that may help predict which ALK-positive lung cancers will respond to PD1/PD-L1 inhibitors. His ultimate goal is to use the findings from his project to develop novel immunotherapy strategies, such as T-cell-based therapies customized to individual ALK patients.



## Targeting the complement pathway in ALK positive lung cancer

**Raphael Nemenoff, PhD**

*University of Colorado Denver, AMC and DC*

Dr. Nemenoff's laboratory is studying a group of proteins called complements. These proteins are an important part of the immune system and protect against bacterial and viral infections.

Recent studies have shown that complements may play a role in cancer progression and metastasis. Dr. Nemenoff's group has found that blocking complement proteins in mouse models of ALK-positive lung cancer prevents the growth of these tumors. His project proposes to test an already FDA-approved complement inhibitor in mouse models of ALK-positive lung cancer, with the goal of taking complement inhibitors to the clinic to treat ALK-positive lung cancer patients.

"We are thrilled to fund such cutting-edge research in the field of immunotherapy for ALK-positive lung cancer. These projects represent the direction in which we want to go. Our voice matters because this research will impact the lives of those in our community," explains Phil Trahan, member of ALK Positive.

"LUNGeivity is proud to be partnering with ALK Positive to identify and drive research projects that have the potential to quickly improve outcomes for ALK-positive patients," says Andrea Ferris, President and CEO of LUNGeivity Foundation. "We're excited that these projects combine the patient voice with the scientific rigor demanded of such critical research, and we are hopeful that they will lead to saved lives."

## A SOLID STEP TOWARD

## The Early Detection of Squamous Cell Lung Cancer



Joshua Campbell, PhD

Joshua Campbell, PhD, Assistant Professor of Computational Biomedicine at Boston University, has been immersed in the field of lung cancer for several years and wanted to find a better way to diagnose patients with squamous cell lung cancer patients, a subtype of non-small cell lung cancer, while the cancer is in early stages. “There is a huge need for research in this area,” he notes. “Improving early detection techniques will be key to improving survival rates for patients with squamous cell lung cancer.”

Squamous cell lung cancer is typically found in the main airways of the lungs and is more strongly associated with smoking than any other type of non-small cell lung cancer. Other factors such as age, family history, environmental factors, and exposure to secondhand smoke can also increase risk for squamous cell lung cancer. Approximately 30% of all lung cancers are classified as squamous.

Patients at increased risk for squamous cell lung cancer can be screened by bronchoscopy, a technique in which a thin tube with a tiny camera attached to one end takes images of the patient’s main airways to look for abnormal regions. These regions can then be biopsied to determine if the patient has squamous cell lung cancer. Although many of these abnormalities are technically classified as premalignant lesions, they often either resolve by themselves or do not progress to become malignant. This leaves physicians in a difficult position, as they do not have the ability to determine which of these regions will likely progress to cancer.

Dr. Campbell’s goal was to study repeat biopsy samples taken from the same patients year after year in order to identify the genomic mutations that were only found in the regions that became cancerous. These mutations could become a test panel for early signs of squamous cell lung cancer. If a premalignant lesion tested positive for these mutations, it could be monitored closely or even treated.

Dr. Campbell found an appropriate set of biopsy samples for this research through a collaboration with Dr. Avrum Spira at Boston University School of Medicine and Dr. Mary Reid at Roswell Park Comprehensive Cancer Center in New York. The samples, ideal for studying premalignant lesions, were taken from a group of patients at high risk for squamous cell lung cancer who were being regularly and repeatedly screened with bronchoscopy. In 2016, Dr. Campbell applied for and was granted a Career Development Award from LUNGevity Foundation to accelerate this critical research. “The three-year award from LUNGevity has been great,” he says. “My professional network of researchers has really grown because of it. And scientifically, it has helped me get my lab off the ground. The research work has gone much faster because I have been able to perform higher-quality deep sequencing of the DNA and hire bioinformatics analysts to help manage the large amounts of data.”

Over the course of this project, the Campbell laboratory has amassed massive amounts of computational data—over 25 terabytes—consisting of whole-exome and deep-targeted sequencing of premalignant samples. Using this data and data previously generated by The Cancer Genome Atlas, Dr. Campbell and collaborators from the Center for Cancer Genome Discovery at Dana-Farber Cancer Institute created a new comprehensive panel that tests for approximately 50 genomic markers that

are associated with squamous cell and adenocarcinoma lung cancers. “It is the most up-to-date lung cancer sequencing panel right now,” explains Dr. Campbell. “And because we studied the genomic sequences so deeply, the panel can identify mutations that are only present in a small proportion of cancer cells within the biopsy.”

While Dr. Campbell’s team has validated the testing panel on a small scale, the panel now requires validation on a larger scale before it can be implemented into routine practice. This involves many high-risk individuals being screened over many years to document which lesions (and which mutations) ultimately result in squamous cell lung cancer. If Dr. Campbell’s panel accurately predicts malignancy, the panel could become widely used by physicians to help identify patients who are at increased risk of squamous cell lung cancer. “It should help us to have a much better idea of which lesions to go after. We should see a decrease in patients with invasive squamous cell lung cancer.”

In addition to finding avenues to evaluate his testing panel on a larger scale, Dr. Campbell will continue his research to understand the underlying mechanisms of squamous cell lung cancer. Through innovative new techniques, he plans to study the genes in individual premalignant cells to gain a more thorough understanding of how squamous cell lung cancer develops.

*“The more we can learn about squamous cell lung cancer, the closer we will get to preventing and curing it. And ultimately, that’s what we are striving for.”*

**JOSHUA CAMPBELL, PHD**

Assistant Professor of Computational Biomedicine, Boston University

## Jennifer Kashatus Joins LUNGeVity Foundation Board of Directors



Jennifer Kashatus, a long-term privacy and cybersecurity professional and partner at DLA Piper LLP, will lend her expertise and passion to further LUNGeVity's work. She brings an important perspective from an industry new to LUNGeVity's board while offering her expertise to further LUNGeVity's work of changing outcomes for people with lung cancer.

Jennifer routinely advises companies in all industry sectors on privacy and cybersecurity issues. In particular, Jennifer assists companies in developing comprehensive global and domestic privacy and data security programs, guiding companies in navigating the myriad state, federal, and international privacy regulations. Jennifer also devotes a significant portion of her practice to incident response and preparation, having advised numerous companies on the implementation of an incident response program and coached

companies through evaluating and responding to a threatened or actual security incident. Further, Jennifer routinely advises clients on privacy and data security matters in the context of corporate transactions, working with clients to identify potential risks in an acquisition, whether buy or sell side.

Jennifer's work with the state, federal, and international regulations will be invaluable as LUNGeVity continues its policy work to improve regulations and legislation impacting lung cancer patients.

*"We are honored to have Jennifer join our board. She brings extensive volunteer experience in the Washington area. Her professional acumen will help guide LUNGeVity on partnering opportunities in many areas. We look forward to working with her to build LUNGeVity's presence."*

**ANDREA FERRIS**

*President and CEO, LUNGeVity Foundation*



### *An Interview with Charles Rudin, MD, PhD*

**RECIPIENT OF LUNGEVITY'S  
2018 FACE OF HOPE AWARD**

**LUNGeVity:** Dr. Rudin, congratulations on receiving the Face of HOPE Award at this year's Celebration of HOPE Gala in New York. What does this award mean to you?

**Dr. Rudin:** It's a great honor to receive this award. I've been associated with LUNGeVity since its inception — it's a wonderful organization that has rapidly grown to be one of the predominant foundations supporting lung cancer research. I'm very pleased to participate on both the Board of Directors and the Scientific Advisory Board. LUNGeVity is a uniquely powerful organization that was greatly needed at the time it came into being, and continues to be needed today.

**LUNGeVity:** What makes you hopeful for lung cancer patients looking forward over the next five years? What's on the horizon?

**Dr. Rudin:** This is an exciting time in lung cancer research. We're seeing a lot of biological insights being translated into improved outcomes for patients.

Immunotherapy has had a major impact. It doesn't work for everyone, but when it does, it can be transformative. This gives us a window into the possibility that even very advanced-stage lung cancer can be treated in a way that leads to long term disease-free survival.

We're very interested in novel ways of activating the immune system to recognize cancers that are not being adequately treated

with immunotherapy. There's also a focus on integrating new therapies into earlier-stage disease. LUNGeVity has been a force in this area, bringing immunotherapy into the pre-surgical arena.

Early detection is ripe for progress. Molecular testing is being refined and improved, finding lung cancer much earlier. Scientists are harnessing new technologies, such as liquid biopsy and biomarkers, so we can intervene earlier, shifting lung cancer diagnosis to earlier stages when the disease can be more easily cured.

**LUNGeVity:** What do you, as a clinician, see as the role of advocacy groups today and in the future? How can we best partner together to help the lung cancer community?

**Dr. Rudin:** Organizations like LUNGeVity can play a key role in promoting progress by engaging patients and families in efforts toward improving outcomes. They can do this by giving a voice to the lung cancer community by directly promoting research through funding.

LUNGeVity has played a particularly key role in launching the careers of young researchers through the Career Development Award program. The CDA program is one of the signature initiatives of LUNGeVity that has attracted talented researchers to focus on lung cancer. It's an investment that plays out over decades, encouraging them to stay in the field and move the science forward for patients.

**ABOUT DR. RUDIN** *Charles Rudin, MD, PhD, is Professor and Chief, Thoracic Oncology Service, at Memorial Sloan Kettering Cancer Center in New York. Dr. Rudin is Chair of LUNGeVity's Scientific Advisory Board and is a member of the LUNGeVity Board of Directors.*

**ABOUT THE FACE OF HOPE AWARD** *LUNGeVity's annual Face of HOPE Award is presented to an individual who recognizes the needs of those living with lung cancer and is actively making a difference.*

# Team LUNgevity Joins the Marine Corps Marathon

ALMOST 30 RUNNERS REPRESENTED TEAM LUNGEVITY AT THE MARINE CORPS MARATHON IN WASHINGTON, DC

LUNgevity's endurance events program, Team LUNgevity, is expanding! Team LUNgevity athletes may choose to participate in one of several official events or run, walk, ride, swim, or compete in a race on their own—all while raising funds for lung cancer research. For the first time ever, Team LUNgevity now includes the opportunity for runners to race as a team in the Marine Corps Marathon in Washington, DC.

Previously, LUNgevity was an Official Charity Partner for five events, including the Bank of America Chicago Marathon, Bank of America Shamrock Shuffle 8K, Transamerica Chicago Triathlon, Chicago Spring Half Marathon & 10K, and Chicago Half Marathon & 5K. The addition of the Marine Corps Marathon to this already impressive set of events is both an honor and another opportunity for those affected by lung cancer to make an impact on the disease.

Join the team! Are you already competing in an endurance event, or are you looking to sign up for one? Join the athletes of Team LUNgevity, who race in endurance events across the US and around the world, to help improve outcomes for lung cancer patients.

## Meet our team—learn more about our Team LUNgevity runners and why they race in our Runner Roster.

**RUNNER** Caroline Brown  
**HOME** Alaska

**RACE** Equinox Marathon  
**QUOTE** I run to support my sister and so many others in their battle against lung cancer.

The course profile of the Equinox Marathon reminds me of the huge and seemingly unconquerable mountain that those dealing with lung cancer face. I want my sister to know that I'm with her every step of the way over that mountain until we get to the other side and find a cure!



**RUNNER** Heather Evers  
**HOME** New York

**RACE** Chicago Marathon

**QUOTE** My friend Jeanine talked with us many times about the fact that there is so much more that needs to be learned about lung cancer, so much more that needs to be done, and that funding for cures and treatments is in such high demand. I know that our efforts to help others in their fight will make her smile.



**RUNNER** Steven Kaganove  
**HOME** Michigan

**RACE** Chicago Marathon

**QUOTE** I am making this commitment because I lost my wife, Miriam, to lung cancer in March 2016, after a determined 2 1/2-year fight. Though she quit running back in high school and never really enjoyed it, I know my wife would be proud of my accomplishments and my determination to honor her memory every time I lace up a pair of running shoes.



**RUNNER** Kyle McCarthy

**HOME** New Jersey

**RACE** Marine Corps Marathon, Ironman Lake Placid, Philadelphia Marathon

**QUOTE** When I was 18, [my father] passed away from lung cancer. I admired how he never gave up and gave that everything he had too. Even though we never had a chance to run a race together, he inspired me to run my first marathon in 2016 with Team LUNgevity. After finishing that race, I decided to set my sights on an even bigger challenge: completing an Ironman in memory of my dad.



**RUNNER** Yovana Portillo

**HOME** Arizona

**RACE** Marine Corps Marathon

**QUOTE** As a lung cancer survivor running a marathon, I hope to inspire others to see that when there is a will, there's a way, and anything you dream of is achievable!



**RUNNER** Melissa Rondi  
**HOME** Colorado

**RACE** Brooklyn Half Marathon

**QUOTE** My sister Emily convinced me to run my first half marathon 4 years ago with her just 3 months after having her first baby, Paige. Now, I am running my second one in honor of Emily, who was diagnosed with stage IV ALK+ lung cancer 3 months ago while pregnant with her second baby, Brady.



**RUNNER** Laura Strutz

**HOME** Pennsylvania

**RACE** Ironman Maryland, NYC Marathon

**QUOTE** I joined Team LUNgevity to compete in my third Ironman to celebrate my 20th "cancerversary" of my breast cancer. I do this to honor my mom, who passed from lung cancer several years ago and for my sister, Susan, who is an 11-year lung cancer survivor and who has been active in LUNgevity. I am proud to honor her and to support this important cause.



**RUNNER** Sara Vargo

**HOME** Virginia

**RACE** Marine Corps Marathon, Lean Horse Ultramarathon

**QUOTE** In 2016, my mother, Deborah, was diagnosed with stage IV lung cancer. As an avid runner, I have decided to use my lungs (and legs!) as a platform to get the word out about lung cancer. I plan to fight the stigma that it only happens to smokers. If you have lungs, you can get lung cancer. I want to raise funds that will help researchers find better treatments, early detection methods, and, hopefully, one day: a cure.



**RUNNER** Frank Wannop

**HOME** Florida

**RACE** Chicago Marathon

**QUOTE** Lori and I were married for 31 years and not a day goes by that I don't think about her. Not only was she my bride, but she was my best friend, and I watched her put up a fight against lung cancer for six years. Running a marathon is a walk in the park compared to what she went through.



## World Lung Cancer Conference, *continued from page 1*

***The goal of Patient FoRCe research projects is to change clinical practice to reflect lung cancer patient (and caregiver) preferences and improve the lived experience of those diagnosed with lung cancer.***

Two of the Patient FoRCe studies presented furthered LUNGevity's Take Aim Initiative, which seeks to ensure that all people diagnosed with advanced-stage lung cancer have access to timely, high-quality, comprehensive biomarker testing.

- Biomarker testing of advanced-stage non-small cell lung cancer (NSCLC) at the time of diagnosis is required to determine if a patient will benefit from a targeted therapy or immunotherapy. A patient may, however, need additional biopsies (rebiopsy) if the cancer recurs, in order to determine the next line of therapy or to determine eligibility for a new drug or participation in a clinical trial. This study, ***Willingness to perform multiple biopsies to improve quality of lung cancer care: Understanding the oncologists' perspective***, complements an earlier study on patient attitudes and demonstrated that rebiopsy routines vary by practice settings (academic cancer center versus community cancer center) and volume of advanced-stage lung cancer patients seen by individual oncologists. Even when rebiopsies are prescribed, a comprehensive biomarker profile of the tumor may not be obtained due to variations in tests requested, leading to potentially suboptimal patient care.
- The second project, ***Identifying gaps in messaging for biomarker testing in the lung cancer community: Need for consistent and actionable messaging***, identified gaps in lung cancer education materials for patients and healthcare providers. The study also reinforced the necessity of including a clear call to action—what patients and healthcare providers (HCPs) should do—in education materials for lung cancer patients and HCPs so that the importance of biomarker testing is appropriately conveyed.

The other two projects underpin LUNGevity's belief that all lung cancer patients should receive "patient-centered" healthcare. This means "care that is respectful of and responsive to individual patient preferences, needs, and values and ensures that patient values guide all clinical decisions." The first step to patient-centered healthcare is equipping the patient (or their caregiver) with information about their disease, so that they feel educated, engaged, and empowered.

- One study, ***Are lung cancer patients receiving education materials? The healthcare provider perspective on distribution gaps and possible solutions***, identified major barriers to distributing patient education materials, such as the lack of standard operating procedures leading to inconsistent delivery of materials. In-depth interviews revealed additional recommendations from HCPs, including customization of information to the patient's type of lung cancer and availability of multiple formats of education materials for distribution. This will help ensure patients receive information.
- The study ***Line of therapy and patient preferences treating lung cancer: A discrete-choice experiment*** is the next phase of Project Transform, which seeks to quantify patient preferences toward different lung cancer therapies and explore how they vary across lines of treatment. The study suggests that patients who have received more than one line of treatment do not care as much about short-term side effects but care more about long-term side effects than do those who have received only one line of treatment.

## Patient-Reported Outcomes, *continued from page 3*

As follow-up to the lung cancer patient meeting with the FDA on this topic, LUNGevity Foundation and members of the FDA co-authored a manuscript, entitled "Patients Demonstrate Lack of Understanding in How PRO Data Are Used: Reflections from a Lung Cancer Patient Roundtable," which was published in the *Journal of Thoracic Oncology* on Monday, October 22, 2018. Through this publication and ongoing efforts, LUNGevity is working to ensure that the patient's values and considerations are at the forefront of regulatory and clinical decision-making.

# CREATE YOUR OWN DIY EVENT



You have the opportunity to create a unique, personalized event for your community through LUNGevity's DIY event program. Whether you are an individual, school, or business, we are able to guide you to an event that works for you. Restaurant give-back nights, painting with the girls, or a school bake sale are only a few of the endless possibilities for a LUNGevity DIY event. It is a great, simple way to impact those affected by lung cancer in your community.

**Find out how you can  
organize your own  
DIY event at  
[lungevity.org/events/  
create-your-own-event](https://www.lungevity.org/events/create-your-own-event).**



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## JOIN US AT THESE FUN AND INSPIRING LUNGEVITY NOVEMBER EVENTS

<b>November 3</b>	Breathe Deep Boca Raton	Boca Raton, FL
<b>November 3</b>	Breathe Deep Boston	Somerville, MA
<b>November 3</b>	Breathe Deep Cincinnati	Cincinnati, OH
<b>November 3</b>	Breathe Deep NYC	New York, NY
<b>November 3</b>	Breathe Deep South Jersey	Pennsauken, NJ
<b>November 4</b>	Breathe Deep Columbus	Columbus, OH
<b>November 4</b>	Breathe Deep DC	Washington, DC
<b>November 10</b>	Breathe Deep Greater Richmond	Richmond, VA
<b>November 10</b>	Breathe Deep San Diego	San Diego, CA
<b>November 17</b>	Breathe Deep DFW	Arlington, TX
<b>November 17</b>	Breathe Deep Stache & Lash	Nashville, TN

For additional information about events near you, visit [www.LUNgevity.org/events](http://www.LUNgevity.org/events)



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