

IN THIS ISSUE

- Survivorship Conference
Draws Record Attendance [page 1](#)
- National Minority Quality Forum [page 1](#)
- Reflections from the Desk of the
President and CEO [page 2](#)
- LUNGeVity Attends ALK Positive
Summit [page 2](#)
- Introducing Ina® [page 4](#)
- A New Wave of Patient Advocacy
Is Here [page 4](#)
- 20th World Conference on Lung
Cancer [page 5](#)
- LUNGeVity 2019 Career Development
Awards: Three Investigators Awarded
[page 6](#)
- Preliminary Results of Project
PRIORITY [page 7](#)
- LUNGeVity Science Receptions [page 7](#)
- Biomarker Testing Success Story:
A Patient's and a Doctor's
Perspectives [page 8](#)
- Lunch & Learn: 13 Lunch & Learns
Held This Fall [page 9](#)
- LUNGeVity Attends Annual
LungCAN Meeting [page 9](#)
- Musical Celebration of Hope
Gala [page 10](#)
- Healthcare Marketing Executive Michael
Parisi Joins LUNGeVity Foundation's
Board of Directors [page 11](#)
- Q&A with Abbie Lynn Abbott,
a member of Team LUNGeVity,
about why she runs [page 11](#)
- Upcoming LUNGeVity Fall and Winter
Events [back cover](#)

Survivorship Conference Draws Record Attendance

The inaugural International Lung Cancer Survivorship Conference, held April 26-28, 2019, boasted three individual summits (HOPE, COPE, and Survivorship) and close to 400 lung cancer patients, survivors, caregivers, physicians, and researchers for a weekend of education, connection, and empowerment. Built on the success of the National HOPE Summit, the International Lung Cancer Survivorship Conference (ILCSC) is dedicated to survivorship and teaching people how to live well with lung cancer.

[continued on page 3](#)



PARTNERSHIP HIGHLIGHT: National Minority Quality Forum

LUNGeVity is proud of its year-long partnership with the National Minority Quality Forum (NMQF)/Sustainable Health Communities, LLC, promoting inclusiveness in lung cancer clinical trials with a focus on racial and ethnic diversity. LUNGeVity is the only lung cancer patient advocacy

group member of NMQF's Diverse Cancer Communities Working Group—a coalition of cancer non-profits, regulators, and industry partners that strive to develop solutions to improve access to care for cancer patients of color and underserved patients. [continued on page 9](#)

Each fall, we publish Fresh Air in time for Lung Cancer Awareness Month in November. While we raise awareness of the facts and challenges of a lung cancer diagnosis, we also reflect on the progress being made for patients. More than ever, we are seeing people who are living well with lung cancer thanks to advances in early detection and treatment.

One way LUNGeivity supports these advances is by funding young investigators through our Career Development Awards. These awards keep outstanding scientists, still early in their careers, in the lung cancer space. You'll learn more about this year's class of researchers and their projects in this newsletter.

You'll also want to read about the inaugural International Lung Cancer Survivorship Conference, built on the success of the National HOPE Summit, which boasted close to 400 lung cancer patients, survivors, caregivers, physicians, and researchers for a weekend of education, connection, and empowerment.

Patients and survivors are also joining together—many by biomarker profile—to make a difference for people living with their type of lung cancer—and to save their own lives. An example of this, Project PRIORITY, is featured in this newsletter. This first-of-its-kind study provides a comprehensive picture of the treatment of EGFR-positive lung cancer patients today. Read more in Advances.

Thank you for your support of LUNGeivity. To learn more and get involved for Lung Cancer Awareness Month, visit www.LUNGeivity.org



Andrea

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.

LUNGeivity Attends ALK Positive Summit

ALK Positive, the patient-driven support group for those with ALK-positive non-small cell lung cancer (NSCLC), held its second annual ALK Positive Summit on August 2-4 in Atlanta, GA. LUNGeivity staff were honored to be part of the program and lend support. The weekend was coordinated by two ALK-positive survivors Amanda Nerstad, ALK Positive Summit Chair, and Gina Hollenbeck, ALK Positive President.

The focus was on the science of ALK-positive lung cancer. Dr. Upal Basu Roy, VP of Research at LUNGeivity, shared promising updates on three research grants selected for funding by ALK Positive following a rigorous review by members of ALK Positive and ALK-positive scientific experts. He also participated in two panels on the future of lung cancer research.

Other speakers included lung cancer advocates Katie Brown (LUNGeivity's VP of Support and Survivorship), Chris Draft, and Dr. Amy Moore; Drs. Alice Shaw, Drew Moghanaki, Christine Lovly, Vincent Lam, and Eslie Dennis; and survivors Linnea Olson and Colin Barton.

We're proud of our partnership with ALK Positive and look forward to our continued work together to improve the lives of lung cancer patients.

BOARD OF DIRECTORS

Alexander F. Stern, Chairman
President, Lazard Ltd.

Tom Galli, Treasurer
Founder, Ingenium Cubed, LLC

Susan Bersh, Secretary
Vice President-Communications, AMLI Residential

Charles Rudin, MD, PhD, Chair, Scientific Advisory Board
Professor and Chief, Thoracic Oncology Service
Memorial Sloan Kettering Cancer Center

Peter Babej
Global Head of Financial Institutions, Citigroup / Global Banking

Patrick Chen
CEO, JD Capital USA

Lynne Doughtie
Chairman and Chief Executive Officer, KPMG LLP

Andrea E. Ferris
President and CEO, LUNGeivity Foundation

Jennifer Kashatus
Partner, DLA Piper, LLP

Michael Marquis
President, Vogue International, a Johnson & Johnson Company

Andre Owens
Partner, WilmerHale

Michael Parisi
Chief Executive Officer, Guidemark Health

Andrew Stern
Founder and Managing Partner, Aurify Brands

Paul G. Stern
Former Presiding Director, The Dow Chemical Company
Former Director, Whirlpool Corporation

SCIENTIFIC ADVISORY BOARD

Scott J. Antonia, MD, PhD
Duke University

Philp D. Bonomi, MD
Rush University Medical Center

Julie R. Brahmer, MD
Johns Hopkins Kimmel Cancer Center
Bloomberg-Kimmel Institute for Cancer Immunotherapy

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

David P. Carbone, MD, PhD
The Ohio State University

Suzanne E. Dahlberg, PhD
Boston Children's Hospital, Institutional Centers for Clinical & Translational Research

Jessica S. Donington, MD, MScR
University of Chicago Medicine and Biological Sciences

Steven M. Dubinett, MD
David Geffen School of Medicine at UCLA

Patrick Forde, MB, BCH
The Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins

Edward W. Gabrielson, MD
Johns Hopkins University School of Medicine

Edward B. Garon, MD
David Geffen School of Medicine at UCLA
Jonsson Comprehensive Cancer Center

John V. Heymach, MD, PhD
The University of Texas MD Anderson Cancer Center

Robert L. Keith, MD
University of Colorado Denver Rocky Mountain Regional VAMC

Benjamin P. Levy, MD
Johns Hopkins University School of Medicine
Johns Hopkins Sidney Kimmel Cancer Center, Washington, DC

Pierre P. Massion, MD
Vanderbilt University School of Medicine

Vanderbilt-Ingram Cancer Center

Drew Moghanaki, MD, PhD
Atlanta VA Medical Center

Emory Winship Cancer Institute

Paul Paik, MD
Memorial Sloan Kettering Cancer Center

Charles M. Rudin, MD, PhD
Memorial Sloan Kettering Cancer Center

Lawrence H. Schwartz, MD
Columbia University Medical Center
NewYork-Presbyterian Hospital/Columbia University Medical Center

Lecia V. Sequist, MD, MPH
Harvard Medical School

Massachusetts General Hospital Cancer Center - Center for Thoracic Cancer

Alice T. Shaw, MD, PhD
Harvard Medical School
Massachusetts General Hospital

Steven J. Skates, PhD
Harvard Medical School
Massachusetts General Hospital

Avrum E. Spira, MD, MScI
Boston University

Johnson & Johnson

Anil Vachani, MD
University of Pennsylvania

Philadelphia VA Medical Center



1) Attendees pose at Welcome Reception 2) Attendees enjoy lively session 3) Lung cancer survivor Greta Kreuz shares personal story 4) Dr. Raja Flores of Mount Sinai participates in "So You've Been Treated—Now What?" session 5) Group photo at ILCSC 2019 6) Cosmetic workshop at ILCSC Expo 7) Group yoga class at ILCSC Expo 8) Nichelle Stigger and Chris Draft at ILCSC Expo 9) Attendees have fun at ILCSC photo booth

International Lung Cancer Survivorship Conference, *continued from page 1*

We welcomed many new faces, including 185 first-time attendees, with participants from many different regions of the country as well as Canada and Australia. There is nothing more hopeful to us than meeting new friends and seeing old friends return. It truly is a family reunion that we look forward to every year!

A new feature this year was the half-day Survivorship Expo on Friday, which included demonstrations, activities, and more than 25 exhibitors. It included a talk about medical marijuana, a boot camp exercise class led by lung cancer survivor Juanita Segura, both chair and regular yoga sessions, and a healthy cooking demonstration.

The ILCSC had three simultaneous tracks: the HOPE Summit for patients, the COPE Summit for caregivers, and the

Survivorship Summit for advocates and survivors who are interested in more advanced topics. The three summits enabled attendees to pick and choose based on their specific needs and lung cancer knowledge base.

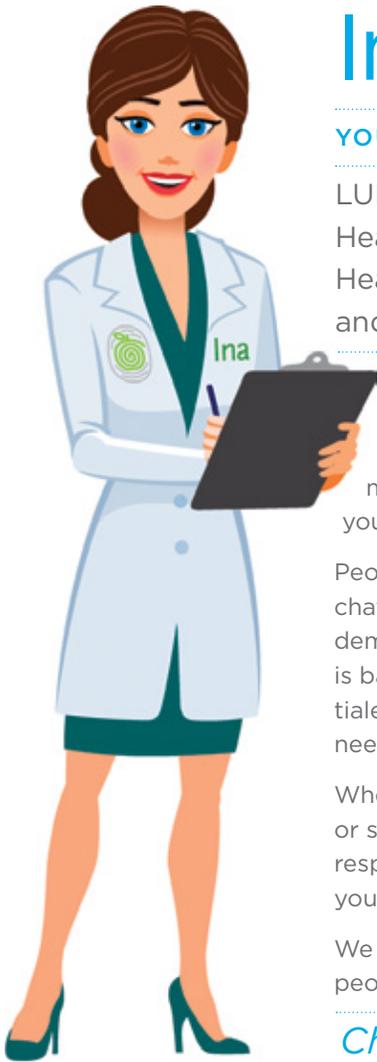
Essential to this year's conference was the addition of the Survivorship Summit. Long-term survivors have very different issues and needs than those recently diagnosed. This summit was planned by a committee of long-term survivors and was truly dedicated to tackling the issues they face, from financial planning to sex therapy. As people begin to live with lung cancer as if it were a chronic disease, LUNgevity is proud to evolve our programs to include and in some cases even focus on long-term survivorship with the help of pioneering survivors.

Some highlights of the 2019 sessions included the Ask the Experts panel with panelists Dr. Paul Paik of Memorial Sloan

Kettering Cancer Center; Dr. Drew Moghanaki of the Atlanta VA Medical Center and Emory Winship Cancer Institute; Dr. Raja Flores of Mount Sinai; Dr. Jose Pacheco of University of Colorado Cancer Center; and Dr. Alice Shaw of Massachusetts General Hospital; the "Living in Limbo" and "You've been Treated—Now What?" sessions for long-term survivors; and the "Sex, Drugs, and Rock and Roll" talk.

As always, a conference favorite was Stories of HOPE, in which patients and caregivers had the chance to share their stories of survivorship. This session, which gave participants the opportunity to learn from and empower each other, was as moving and powerful as in years past.

LUNgevity is proud of the community, education, and support we are able to provide over the course of the weekend. We can't wait to see everyone at the second ILCSC on April 24-26, 2020!



Introducing Ina®

YOUR PERSONAL INTELLIGENT NUTRITION ASSISTANT FROM SAVOR HEALTH®

LUNGeivity is proud to announce the expansion of our partnership with Savor Health® to bring Ina®, your personal Intelligent Nutrition Assistant from Savor Health®, to our patient community. Ina® helps people with cancer eat healthy and stay well nourished throughout their treatment and beyond.

When you're navigating a lung cancer diagnosis, nutrition can be an important part of your journey. Eating a well-balanced diet before, during, and after treatment can help you feel better, maintain your strength, help manage symptoms, and speed your recovery.

People with cancer and their caregivers can communicate with the chat bot 24/7 to receive personalized, clinically appropriate, and "on demand" nutrition support and guidance. Ina®'s knowledge and advice is based on scientific evidence and the training of oncology-credentialed registered dietitians, nurses, and doctors who are experts in the needs of cancer patients.

Whenever you'd like answers to questions about your nutrition needs or symptom management, text Ina® from your cell phone; she'll respond with personalized nutrition tips, recipes, and answers to your questions—no phone calls or appointments are necessary.

We are proud to add this nutritional resource to our offerings, helping people live well with lung cancer.



Check out Ina® for yourself by visiting LUNGeivity.org/ina.

A New Wave of Patient Advocacy Is Here

The last few years have seen rapid advancement in treatment options for people living with lung cancer. With the success of targeted therapies and immunotherapy, many patients are not only living longer, they are also living better.

Many of today's lung cancer patients are going back to work, traveling, and enjoying family milestones. They are also joining together—many by biomarker profile—to make a difference for people living with their type of lung cancer—and to save their own lives.

LUNGeivity is proud to be partnering with several of these patient groups to share expertise and the resources they need to be successful. We became the fiscal sponsor of ALK Positive in 2018, supporting their fundraising efforts. Also, with the participation of the ALK Scientific Review Committee comprising ALK Positive

members and renowned ALK-positive researchers, research awards were selected that have the ability to impact the ALK-positive community.

Our partnership with the EGFR Resisters has led to the presentation of a needs assessment paper for the EGFR community, Project PRIORITY, at the World Conference on Lung Cancer in Barcelona in September and in October in Chicago at the North American Conference on Lung Cancer (both IASLC events). The Patient Reported Initiative On Resistance, Incidence, Treatment StudY (PRIORITY) is a patient-founded and patient-driven

research partnership between the EGFR Resisters and LUNGeivity Foundation. The study team is interested in understanding the treatment experience of EGFR-positive lung cancer patients.

LUNGeivity was excited to brand the RET Renegades to assist in building the community on Facebook. The private group resides on the LUNGeivity Facebook page to serve the concerns of this lung cancer group.

We look forward to seeing what these and other similar groups can tackle and accomplishing going forward.

advances

20th World Conference on Lung Cancer



REFLECTIONS FROM DR. UPAL BASU ROY, LUNGEVITY'S VICE PRESIDENT OF RESEARCH

This year's International Association for the Study of Lung Cancer World Conference on Lung Cancer (WCLC) in Barcelona, Spain, was the biggest ever, attracting more than 7,500 patient advocates, researchers, clinicians, and drug developers from 116 countries.

Participation in the STARS program: Much of my time at WCLC this year was spent in my role as a mentor to an advocate from Nigeria in the IASLC inaugural Supportive Training for Advocates on Research and Science (STARS) program. This new program aims to increase the number of Patient Research Advocates (PRAs) equipped to provide accurate scientific translation in their online or real-life lung cancer patient/caregiver groups, and to provide the patient perspective for lung cancer research and policy. Research advocacy, which is different from patient advocacy, entails patient and caregiver involvement in deeper aspects of research, such as providing feedback on research studies and study designs, dissemination of complex scientific information to the community at large, and helping patients find and enroll in clinical trials. Composed this year of five mentees and five mentors from different countries, the STARS program fills this important unmet need in lung cancer research advocacy.

Early Detection and Early-Stage Lung Cancer: The National Lung Screening Trial (NLST) established in 2011 that low-dose computed tomography (LDCT) scans help detect lung cancer in high-risk individuals. However, LDCT has a high rate of false positives: 95% of lung nodules detected in LDCTs are non-cancerous. This year's plenary session included several presentations on combining LDCT with blood-based biomarker tests, such as the EarlyCDT®-Lung Test or a microRNA test described in the BioMILD trial, to help make LDCTs more sensitive. How such tests can be implemented on a large scale is being researched.

A British study comparing video-assisted thoracic surgery (VATS) with open lobectomy for early-stage lung cancer reveals that use of VATS leads to fewer in-hospital complications and a shorter hospital stay after surgery. It was great to see studies such as this, which clearly demonstrate the impact of treatment strategies on the quality of life of patients.

Biomarker-driven targeted therapies: No lung cancer conference is complete without highlights on targeted therapies. The drug



STARS mentors and mentees at the 20th World Conference on Lung Cancer

AMG510, which targets a specific mutation in the KRAS gene, the G12C mutation, is continuing to show promise in early clinical trials. This is a huge step, given that the KRAS gene has been long considered "untargetable" despite the fact that mutations in the KRAS gene are found in 25% of adenocarcinomas. Another drug, selipercatinib (also known as LOXO-292), is very effective, as seen in the LIBRETTO-001 clinical trial, in lung cancers positive for a fusion in the RET gene. Such fusions are rare in lung cancer and seen in 1%-2% of adenocarcinoma patients. The success of these two trials reminds us that the first step to accessing such targeted therapies is access to comprehensive biomarker testing. Since 2015, LUNGEvity has been advocating for comprehensive biomarker testing through our Take Aim Initiative.

Immunotherapy: Analysis of data collected through two clinical trials (CheckMate 017/057) demonstrate that non-small cell lung cancer (NSCLC) patients taking nivolumab experienced a five-fold increase in 5-year survival rates compared with those patients who received chemotherapy. This study clearly shows that immunotherapy may provide long-lasting responses in patients who respond to immunotherapy. Results from the Impower131 study presented at this year's meeting show that

continued on page 7

LUNGEVITY 2019 CAREER DEVELOPMENT AWARDS:

Three Investigators Awarded

LUNGeVity Foundation is proud to present three outstanding researchers with a 2019 Career Development Award (CDA): Drs. Joshua Bauml, Wei-Chu Victoria Lai, and Aaron Lisberg. These substantial financial awards serve two purposes: they fund critical lung cancer research projects while offering the recipients financial support and guidance early in the careers.

LUNGeVity CDAs are awarded to early-career researchers whose proposals demonstrate potential for either detecting lung cancer early, when it is most treatable, or extending and improving the lives of lung cancer patients with new treatment options. The CDA program encourages the awardees to continue their development in lung cancer research to ensure a strong pipeline of dedicated lung cancer researchers. To date, LUNGeVity has offered this award to 26 researchers.

The 2019 awardees are focused on two important questions:

- How can we increase the number of advanced-stage NSCLC patients who respond to immunotherapy?
- How can we reverse small cell lung cancer patients' inevitable resistance to chemotherapy?

All three of these projects involve approaches to enhancing current treatments.

JOSHUA BAUML, MD

Perelman School of Medicine—University of Pennsylvania

Abramson Cancer Center

Phase II study of pembrolizumab and itacitinib (INCB39110) in NSCLC

The lung cancer treatment landscape is rapidly evolving with the advent of immunotherapy. Three checkpoint inhibitors are currently available as monotherapy in the first-line and second-line settings for certain subsets of advanced-stage NSCLC patients. Despite this promise, a large subset of patients treated with immunotherapy will not respond to



Joshua Bauml, MD

these drugs. This lack of response may be attributed to immune suppressive mechanisms such as interferon signaling. Dr. Joshua Bauml's laboratory is studying pathways that block interferon signaling, such as the JAK-STAT pathway. He proposes to conduct a phase 2 combination-therapy clinical trial, pairing pembrolizumab, an immunotherapy, with itacitinib, a JAK-STAT pathway inhibitor, in advanced-stage NSCLC patients. Dr. Bauml postulates that the combination regimen will remove the immune suppressive effects of interferon signaling and enhance the action of pembrolizumab. He will also be collecting tumor and blood samples during the course of the trial and will characterize these samples to identify molecular predictors of response in patients.

WEI-CHU VICTORIA LAI, MD

Memorial Sloan Kettering Cancer Center

Overcoming chemoresistance through epigenetic modifications in SCLC

Small cell lung cancer (SCLC) comprises 15% of all diagnosed cases of lung cancer. The cancer usually responds to initial chemotherapy; however, it inevitably becomes resistant to the chemotherapy and progresses. Identifying strategies to reverse chemoresistance in SCLC continues to be an unmet need. SCLC cells produce high amounts of a protein called EZH2. This protein helps SCLC cells escape the effects of chemotherapy. DS-3201b is a drug that blocks the effects of EZH2. Dr. Lai will conduct a phase 1 clinical trial with DS-3201b in extensive-stage SCLC patients receiving chemotherapy. The goal of the trial is to



Wei-Chu Victoria Lai, MD

determine whether the addition of DS-3201b to chemotherapy prevents the development of chemoresistance in SCLC patients.

AARON LISBERG, MD

University of California, Los Angeles

Intratumoral CCL21-gene modified dendritic cells with pembrolizumab in NSCLC

Current immunotherapy strategies work only in a subset of advanced-stage NSCLC patients. There remains an unmet need to improve immunotherapy modalities so that a larger patient population may benefit from this novel treatment regimen. One hypothesis is that current checkpoint inhibitors do not work in all patients because specialized immune cells called T-cells (the target of immune checkpoint inhibitors) are unable to home in on their tumors (these tumors are referred to as "cold" tumors). Dr. Aaron Lisberg is studying a novel combination immunotherapy approach—administering a checkpoint inhibitor, pembrolizumab, with genetically modified immune cells derived from a patient. Dendritic cells are immune cells that help other immune cells such as T-cells in identifying and homing in on a cancer. Dr. Lisberg's laboratory will genetically manipulate a patient's dendritic cells to artificially produce a protein called CCL21 (CCL21-DCs). He proposes that combining these CCL21-DCs will help recruit T-cells to a patient's tumor and make them responsive to the immune checkpoint inhibitor (in other words, turn a cold tumor into a hot one).



Aaron Lisberg, MD

Preliminary Results of Project PRIORITY

Project PRIORITY (Patient Reported Initiative On Resistance, Incidence, Treatment Study), a collaboration between LUNGeVity Foundation and the EGFR Resisters—a grassroots, patient-driven community dedicated exclusively to changing EGFR-positive lung cancer into a manageable chronic disease—aims to understand unmet needs of the EGFR-positive lung cancer community.

Project PRIORITY kicked off in April 2019 with an international, longitudinal survey aimed at understanding the diagnostic and treatment journey of EGFR-positive patients. Preliminary results (the study is ongoing) were presented at IASLC's 20th World Conference on Lung Cancer in Barcelona by Ivy Elkins, lung cancer survivor and co-founder of the EGFR Resisters. Thus far, there have been three key findings.



Ivy Elkins

First, patients are not receiving biomarker testing, the initial step to accessing precision medicine. Biomarker testing is required to match a patient to the right treatment at the right time. Results from the EGFR-positive lung cancer community demonstrate that only around 40% of patients in the US and 10% of patients outside the US received some form of comprehensive biomarker testing, either as part of their diagnosis or at progression or recurrence.

Second, EGFR-positive patients have a much lower history of active tobacco exposure (only 16% report active tobacco expo-

sure) and a much higher history of passive tobacco exposure (35%), consistent with previous published studies, indicating that this community of patients has a different epidemiological profile compared to the general lung cancer patient population. This consistency is especially important since it demonstrates that findings from Project PRIORITY may be generalizable to the EGFR lung cancer population.

Third, patients are still not receiving the FDA-approved standard of care as their first drug (first-line treatment). Only 35% of patients in the US and 17% of patients outside the US report receiving the standard of care, the EGFR TKI Tagrisso® (osimertinib).

This first-of-its-kind study provides a comprehensive picture of the treatment of EGFR-positive lung cancer patients in the real-world setting and highlights the existence of diagnostic and treatment gaps both within the US and internationally. We look forward to learning more about this unique patient population as the study progresses.

20th World Conference on Lung Cancer, *continued from page 5*

the addition of the immunotherapy drug atezolizumab to the current standard of care, chemotherapy (carboplatin/nab-paclitaxel), for squamous cell lung cancer improves patient outcomes. This benefit was seen in patients whose tumors express high levels of the PD-L1 protein. These studies continue to demonstrate that immunotherapy is here to stay. It is, however, becoming more and more evident that immunotherapy combinations are more likely to be used rather than single-agent immunotherapy.

Small cell lung cancer: Results of the CASPIAN trial show that the immunotherapy (durvalumab)-chemotherapy (etoposide and platinum drugs) combination is better than chemotherapy alone in small cell lung cancer (SCLC) patients in the first-line setting. The CASPIAN trial is a great step in the right direction—adding a new treatment option for SCLC, a highly aggressive type of lung cancer that has seen less treatment progress than non-small cell lung cancer (NSCLC). Another area of investigation in SCLC is the use of PARP inhibitors in combination with other treatment approaches. SCLC cells produce high amounts of the PARP protein, which in turn, makes these cells resistant to chemotherapy. A PARP inhibitor, olaparib, in combination with temozolomide is showing promise in a phase 1/2 clinical trial.

I left Barcelona with optimism and a firm commitment to continue to advocate for research that is meaningful to the lung cancer community. Adéu, Barcelona, and jumpa pada tahun depan (see you next year!), Singapore.

LUNGeVity Science Receptions

PATIENTS, CAREGIVERS, RESEARCHERS, AND INDUSTRY PARTNERS CONNECT FOR AN EVENING OF CONVERSATION

Last spring, LUNGeVity hosted our Science Receptions in Boston and New York that brought together lung cancer patients/survivors and their families and leaders in business, research, and science.

These unique events brought together diverse members of the lung cancer community who do not frequently interact. It is our hope that these types of interactions can help break down communication barriers between these groups and form new understanding among participants.

LUNGeVity is proud to continue to convene meetings and events that break down silos and better incorporate patients and caregivers into the conversation around the disease. Events like these lead to innovative thinking, research, and ultimately, better treatment.

We thank everyone who attended these special events.

Biomarker Testing Success Story

A PATIENT'S AND A DOCTOR'S PERSPECTIVES

One of the most important steps that someone with advanced-stage non-small cell lung cancer (NSCLC) can do for their care is have comprehensive biomarker testing at diagnosis and at progression or recurrence of their lung cancer. The results of this testing will tell a patient and their care team whether they have any one of a number of possible genomic alterations for which there is a targeted therapy and what their level of a certain protein (PD-L1 protein, to determine whether immunotherapy is likely to be effective) is. This is critical information for making optimal treatment decisions.

Melissa Crouse, a former middle school orchestra and chorus director and 14-year lung cancer survivor from Cape Coral, FL, learned how important this information can be. One of Melissa's primary oncologists, Justin Gainor, MD, from Massachusetts General Hospital, offers his insights on the situation as well.



PATIENT, Melissa Crouse

I was diagnosed in 2005 with stage 2A NSCLC when an x-ray showed a tumor in the upper lobe of my left lung. After my diagnosis, the hospital ran single-gene biomarker testing for the EGFR mutation. This was the only testing they knew to do then, and those results were

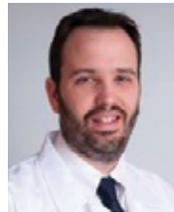
negative. I was treated with surgery and chemotherapy.

In November 2012, seven years after my initial diagnosis, a new oncologist performed comprehensive biomarker testing and discovered that my tumor tested positive for the RET marker. My reaction was, "All right. So what does that mean?" There wasn't a RET therapy approved or anything even in clinical development.

Over the course of several years, my oncologist put me on four multi-kinase clinical trials, none of which were developed specifically for RET mutations, and these kept me alive for six years. None of the clinical trials or the immunotherapy really worked, and they all made me really sick because they were not targeting my specific mutation. Emotionally, I felt defeated.

After Dr. Gainor became my oncologist, I remember asking him about next steps, and he told me that there was a new clinical trial for RET starting up. Although my hospital, Mass General, was going to be a site for the trial, it wasn't open yet. He wanted to get me on the clinical trial right away, and he knew the oncologist who was the principal investigator for the recently opened RET clinical trial at Memorial Sloan Kettering in New York City. That's the trial I got on in July 2017.

It was two years in July 2019 since I started my RET study, and I feel remarkably well. I enjoy a good quality of life and now spend as much time as possible with my grandchildren. I'm actually able to function and do "normal" things like meeting friends for lunch, going to the beach, going to church, and shopping—activities I couldn't even think about with the other clinical trials I've been on that were not targeting RET. I was just too sick. Now, things are very different.



DOCTOR, Justin Gainor, MD

Sometimes, the drug development process can lag behind the science a bit. Take RET fusions as an example: they were identified in lung cancer around 2012. At the time, there were multiple targeted therapies, but nothing for RET. All indications were that RET fusions

were biologically similar to other fusions, namely ALK and ROS1. So, people started looking at whether we could target RET-positive tumors the same way we do for ALK- and ROS1-positive tumors. At the time, our drugs were relatively limited and we were really using repurposed inhibitors that weren't designed to target RET.

Fortunately, there was a concerted effort to catch up with the science and develop better and more selective RET inhibitors. In the last two years, we've seen the emergence of two selective RET inhibitors (LOXO-292 and BLU-667) that are available in clinical trials. These new RET inhibitors have much higher response rates and improved tolerability compared to what we saw with the multi-kinase inhibitors of five years ago. This really underscores that using science to guide the identification of new therapeutic targets, while coupling this with development of cleaner drugs, can produce a transformative outcome for patients.

Today, it is inadequate just to test for the markers with approved drugs because there are very, very promising targets out there with therapies in clinical development. For example, MET Exon 14 skipping mutations and RET fusions are genomic alterations for which we have some very, very promising data using targeted therapies in clinical trials.

My recommendation is for all advanced NSCLC patients to have broader, multiplex biomarker testing, which means that the tumor tissue tested for all of the markers is done at the same time via next-generation sequencing for targeted therapies and PD-L1 testing for immunotherapies.

If you've been diagnosed with non-small cell lung cancer (NSCLC), you should ask your doctor about comprehensive biomarker testing. Learn more at [LUNGeVity.org/biomarkertesting](https://www.LUNGeVity.org/biomarkertesting).

LUNCH & LEARN

13 LUNCH & LEARNS HELD THIS FALL

This fall, LUNGeivity will be hosting Lunch & Learns across the country as part of our national community and education program. Lung cancer patients, caregivers, and healthcare providers join us to hear from experts about the fast-changing field of lung cancer treatment, learn about local resources, and connect with other people affected by lung cancer.

These events address the most pressing topics in lung cancer today. Some popular topics from the events include “The Value of Screening and Minimally Invasive Surgery” and “What to Expect from Your Pulmonologist from A to Z.” Every event hosted encourages attendees to network and support each other and also includes a presentation of available local and national resources.

Come join us next year at a Lunch & Learn near you!

Learn more at www.LUNGeivity.org/lunch-learn.

#GivingTuesday

First, there was Black Friday.
Then came Cyber Monday.
And now, #GivingTuesday!

Please mark your calendars for Tuesday, December 3rd, when LUNGeivity Foundation joins this global day of giving that kicks off the charitable season. #GivingTuesday celebrates and supports giving and philanthropy during the season when many of our generous donors focus on their holiday and end-of-year giving.

Visit www.LUNGeivity.org on Tuesday, December 3rd, to make your donation!

National Minority Quality Forum, *continued from page 1*

An important focus of the Working Group is inclusiveness of racial and ethnic minority groups (REMGs) in cancer clinical trials. Participation of REMGs in cancer trials is disproportionately low despite a high prevalence of certain cancers in REMG populations. LUNGeivity Foundation recently participated in a collaborative research project with the Diverse Cancer Communities Working Group that aims to codify best practices to increase recruitment of racial and ethnic minority populations into clinical trials so that these populations are able to access

life-saving treatments. Findings from this project were encapsulated in a manuscript entitled “US Cancer Centers of Excellence Strategies for Increased Inclusion of Racial and Ethnic Minorities in Clinical Trials,” which was published in the *Journal of Oncology Practice* in April 2019.

LUNGeivity has also concluded a clinical trial mapping study with NMCF to map lung cancer clinical trials and areas of high prevalence of lung cancer (with data obtained from the Centers for Medicare and Medicaid Services). The mapping exercise demonstrates that of the areas of high prevalence of lung cancer, only 10.5% had non-small cell lung cancer (NSCLC)

LUNGeivity Attends LungCAN Meeting

The annual two-day meeting, hosted in San Carlos, CA, brought together members of lung cancer, pan-cancer, and patient support organizations and lung cancer patients as well as industry representatives to share best practices and explore areas for collaboration to improve outcomes for people diagnosed with lung cancer.

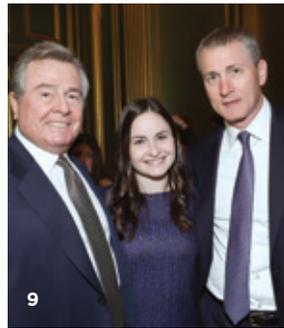
Nikki Martin, LUNGeivity’s Director of Precision Medicine Initiatives, represented the Foundation. “As a first-time participant, I was struck by the great exchange of information with one another, and with industry. It was a valuable two days.”

LungCAN is a collaborative group of lung cancer advocacy organizations that have come together to raise public awareness about the realities of lung cancer.

During the past year, LungCAN members collaborated on a Biomarker Testing Advocacy Program on “consistent testing language” managed by LUNGeivity. LungCAN members will soon vote on projects to elevate as collaborative efforts in 2019-2020.

Following up on a discussion at the LungCAN meeting, LUNGeivity hosted a webinar on the proposed reversal of CMS’s 14-Day Rule that would create barriers to patient access to timely comprehensive biomarker testing. In 2017, the patient advocacy, laboratory and pharma/biotech communities worked together to overturn this Rule. The webinar included specific calls-to-action for the patient advocacy community. LUNGeivity will report on the outcome of our joint efforts.

trials while only 5.6% percent had small cell lung cancer (SCLC) trials. These gaps were exacerbated in regions with high density of African American and Asian American lung cancer patients. Findings from this study have been summarized in an abstract entitled “Geographic relationship between lung cancer clinical trial sites and patient prevalence and demographics in the Medicare Fee-for-service program” presented at the 12th AACR Conference on The Science of Cancer Health Disparities in Racial/Ethnic Minorities and the Medically Underserved on September 20-23, 2019.



1) Lung cancer survivors Amanda Kouri and Greta Kreuz help facilitate the Gala auction 2) Paul Kluetz, FDA; Doug Kammerer, Emcee; Andrea Ferris, LUNGEVITY's CEO, and Mark Jacobstein, awardee 3) Ballroom on the evening of the Gala 4) Face of Hope Awardee Dr. Julie Brahmer with her team from Johns Hopkins 5) Awardee Dr. Julie Brahmer and her family 6) Attendees of the Musical Celebration of Hope Gala participate in the Gala auction 7) Gala Chair Natalie Cohen Smith delivers remarks at the event 8) Natalie Cohen Smith and family at the Gala 9) Board members Paul Stern and Alex Stern with Arielle Stern 10) Lung cancer survivors and caregivers at the Gala

Musical Celebration of Hope Gala

The 8th annual Musical Celebration of Hope Gala in DC in April 2019 was a great success. Leaders of business, philanthropy, and science gathered to raise funds for LUNGEVITY's research, education, and support programs.

This year's event was chaired by Natalie Cohen Smith, whose young husband, Joey, died of lung cancer at the age of 33. Vice Chairs were lung cancer survivors, Greta Kreuz and Larry Aschenbach.

Each year, LUNGEVITY honors individuals and organizations whose commitment and efforts to improve outcomes for lung cancer patients are making a difference. Honorees at the 2019 DC Gala included

Guardant Health (Hope Award for Corporate Leadership) and Julie Brahmer, MD, MSc, FASCO (Face of Hope Award). Dr. Brahmer is a professor of oncology at Johns Hopkins Kimmel Cancer Center, Bloomberg-Kimmel Institute for Cancer Immunotherapy, as well as Director of the Thoracic Oncology Program and Director of Johns Hopkins Kimmel Cancer Center at Bayview. She is also a member of LUNGEVITY's Scientific Advisory Board.

There were close to 400 attendees. Included among them were 40 survivors and 20 doctors and researchers, as well as Gala and national sponsors who supported the event.

With the help of Vice Chair Greta Kreuz, survivor Amanda Kouri, and a professional auctioneer, LUNGEVITY surpassed all prior DC event-night fundraising.

Healthcare Marketing Executive Michael Parisi Joins LUNGevity Foundation's Board of Directors

Michael Parisi, CEO at Guidemark Health, has joined LUNGevity's Board of Directors. His experience at Guidemark Health, a diversified healthcare communications agency with a focus on oncology and rare diseases, will be instrumental to the Foundation in its work of changing outcomes for people with lung cancer.



Michael brings an indispensable perspective with his many years of experience working in healthcare communications. His knowledge from other diseases can

be translated and adapted to lung cancer, allowing him to help strategically guide the Foundation. Michael's professional connections will also help ensure that the Foundation is partnering with the best organizations for each of its initiatives, resulting in important progress for patients.

Michael has over 25 years of diverse healthcare industry experience with an intense focus on biotechnology and oncology. Prior to Guidemark Health, he spent 17 years within the Ogilvy Healthcare organization, where he worked across all aspects of the oncology marketplace, creating long-standing partnerships with many biopharma companies and academic centers on the cutting edge of cancer research.

Named to the PharmaVOICE 100 Most Inspiring Healthcare Leaders in 2016 for his leadership and innovation in cancer and

rare diseases, Michael is a recognized leader and cancer advocate. He currently serves as the President of the Board of Trustees of CancerCare, a partner of LUNGevity. Additionally, for the past seven years, he has served on the board of the NCCN Foundation, the philanthropic affiliate of NCCN and an organization that represents 28 of the nation's leading cancer centers.

LUNGevity looks forward to working with Michael to help improve outcomes for and the lives of people affected by lung cancer.



Q&A with Abbie Lynn Abbott, a member of Team LUNGevity, about why she runs

Abbie Lynn Abbott completed her first marathon—the 2018 Bank of America Chicago Marathon—in honor of her mother, who was diagnosed with lung cancer in 2018. Shortly after the race, her mother passed away. This year, Abbie is running the Marine Corps Marathon with Team LUNGevity in memory of her mom and to honor those living with the disease. Originally from southern Indiana, she now lives in central Florida with her husband and three children.

How did you first get involved with LUNGevity as a fundraiser?

My family and I heard about LUNGevity after my mother was diagnosed with stage IV lung cancer. My brother and I had just completed our first marathon 15 days prior to our Momma's passing. Although we ran for a different charity in the Chicago marathon, we immediately knew that we wanted to run again, and this time in our precious Momma's memory. We quickly found the Marine Corps Marathon and Team LUNGevity, and we knew this was the team for us.

What impact do you hope your fundraising efforts will make?

I did not realize how under-funded and under-researched lung cancer is in our country. I hope that our efforts will bring lung cancer more awareness and funding. Our sweet Momma may not have received the happy ending for which we were hoping, but others might be able to beat the odds if we raise more awareness and funds. Her lung cancer story doesn't have to be everyone's lung cancer story.

What advice would you give to someone who is looking to start fundraising for lung cancer?

We felt overwhelmed and ill-equipped to do much, but we realized that it wasn't our job to beat the disease alone. It is our job to simply take steps toward awareness. One of my favorite quotes is from Edmund Burke. He says, "Nobody makes a greater mistake than he who does nothing because he could only do a little." I think my biggest piece of advice would be to simply do something. Even if that something is small, it can make a difference.

Do you have any training advice for new runners?

Take one step at a time! I get frustrated sometimes when I don't get all of my mileage in during a week, but I have to remind myself that every mile is another mile closer to the finish line. Even if you can only get one mile in today, that's ok. Maybe the next run will be 1.5 miles. One step at a time. One mile at a time.

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 participate in endurance events across the US and around the world, to help improve outcomes for lung cancer patients. Find out more at www.LUNGevity.org/TeamLUNGevity.



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



JOIN US AT THESE FUN AND INSPIRING **LUNGevity** FALL & WINTER EVENTS

| | | |
|--------------------|---|-------------------|
| November 1 | Lunch & Learn Cancer Treatment Centers of America | Philadelphia, PA |
| November 2 | Breathe Deep Boston | Somerville, MA |
| November 2 | Breathe Deep South Jersey | Pennsauken, NJ |
| November 2 | Lunch & Learn UChicago Medicine | Chicago, IL |
| November 3 | Breathe Deep DC | Washington, DC |
| November 3 | TCS New York City Marathon | New York City, NY |
| November 6 | Celebration of Hope Gala | New York City, NY |
| November 9 | Breathe Deep Greater Richmond | Richmond, VA |
| November 9 | Lunch & Learn Texas Presbyterian Hospital | Plano, TX |
| November 16 | Lunch & Learn The James Cancer Center and Solove Research Institute | Columbus, OH |
| November 16 | Lunch & Learn CR Wood Cancer Center | Glens Falls, NY |
| November 16 | Lunch & Learn Cancer Pathways | Seattle, WA |
| November 21 | Lunch & Learn Moffitt Cancer Center | Tampa, FL |
| December 6 | Lunch & Learn Sentara CarePlex Hospital | Hampton, VA |

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



CHICAGO OFFICE 228 S. Wabash Ave., Suite 700, Chicago, IL 60604 **PHONE** 312.407.6100
BETHESDA OFFICE 6917 Arlington Rd., Suite 352, Bethesda, MD 20814 **PHONE** 240.454.3100
WEBSITE www.LUNgevity.org **EMAIL** Info@LUNgevity.org