UPDATES ON PROGRESS IN IMPROVING OUTCOMES OF LUNG CANCER

Volume 7, Issue 2

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Upcoming Breathe Deep Spring and Summer Events back cover

New Partnership Empowers Patients to be Partners in Research

Institute of MIT and Harvard to give patients the opportunity to make a lasting impact on the future of lung cancer diagnoses and treatments.

Through the partnership, lung cancer patients undergoing a surgical resection or a drainage for pleural effusion will be able to direct their excess cancer tissue and fluid samples to the Broad Institute's Cancer Cell Line Project by consenting through Pattern.org.

Pattern.org coordinates the biologistics of sample collection and delivery. These samples will be used in the development of next-generation research models (cell line and organoid). The models will enable researchers to better understand the vast genetic diversity among lung cancers and, ultimately, speed the development of new diagnostics and therapies. All created models and associated data will be shared broadly with the scientific community. "A key barrier for researchers is the lack of cell line models to study how the cancer

behaves and how it responds to different drugs," says Upal Basu Roy, PhD, MPH, Senior Director of Research at LUNGevity. "LUNGevity is excited to offer lung cancer patients a platform to provide lung cancer researchers with the tissue they need to learn about the disease. We believe that patient-driven

research will significantly accelerate progress for lung cancer patients."

The partnership with Pattern.org and the Broad Institute strengthens LUNGevity's commitment to drive translational research to increase treatment options for patients. institutions and universities.

Patients who have an upcoming surgery or drain at any institution in the continental US are invited to visit www.LUNGevity.org/ drive-research to learn more about how to donate their samples.

LUNGevity Convenes Multi-Stakeholder Meetings for Biomarker Testing

LUNGevity strives to ensure that getting the right treatment or care plan at the right time is possible for all lung cancer patients. This requires comprehensive biomarker testing as a first step. In March 2019, LUNGevity convened two roundtables to discuss the most effective means of overcoming barriers to biomarker testing for patients: the Pan Tumor Patient Advocacy Best Practices Roundtable and the Nursing and Nurse Navigator Roundtable.



continued on page 4



SPRING 2019

REFLECTIONS FROM THE DESK OF THE PRESIDENT AND CEO

With spring comes the last sprint to the close of our fiscal year, and we take stock of all we've accomplished.

This spring, LUNGevity released a report showcasing the organization's impact on the rapidly advancing field of lung cancer research and patient care. Thanks to your ongoing support, our accomplishments in research, patient services, major initiatives, and more are helping to drive progress in all areas for people living with lung cancer.

LUNGevity has also designated May as Lung Cancer Hope Month. We're dedicated to fostering an increasingly active lung cancer community more empowered patients, more long-term survivors, and more people living well with lung cancer.

I'm proud of the work that LUNGevity is doing to improve outcomes for people diagnosed with lung cancer and I applaud all on our team, and all of our constituents, who are making change happen. We have the greatest impact when we work together.

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

Andira

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.



Raising Awareness about Biomarker Testing

In November 2018, LUNGevity launched a new awareness campaign in its Inhale for Life series to encourage newly diagnosed, advanced-stage NSLC patients to speak with their doctor about biomarker testing. Using social media, a :30 PSA, and six compelling patient stories, Inhale for Life: Biomarker Testing ran from November 2018, to coincide with Lung Cancer Awareness Month, through March of this year.

The campaign showed great results, reaching half a million people with a total of 96,384 full video views, and over 1,100 people signing up to learn more. Inhale for Life: Biomarker Testing was supported in part by grants from AstraZeneca and Genentech. LUNGevity also offered a Spanish version of the PSA and one patient video.

Stay tuned for the next video in the Inhale for Life series, which will be focused on the importance of clinical trials.

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LUNGevity and CancerCare[®] Seek to Understand the Financial Burden of Lung Cancer Treatment

LUNGevity's research institute, Patient FoRCe, and the patient advocacy organization CancerCare® recently concluded a collaborative study among their constituents that assessed the burden of financial toxicity on lung cancer patients.

"Financial toxicity," also known as "financial distress," is a term that refers to financial problems that arise for a patient or their caregiver due to the cost of cancer treatment that isn't covered by insurance.

The results clearly suggest that a lung cancer diagnosis can be a financial stressor for both patients and caregivers. While participants from both LUNGevity and CancerCare® reported some form of financial toxicity (the costs associated with travel to access treatment seemed of particular concern to both groups), the financial impact of a lung cancer diagnosis is more apparent in the CancerCare® population. This differential impact is important to note given that LUNGevity and CancerCare® serve unique populations,



and suggests that financial programs need to take into consideration social determinants of health, such as race and ethnicity and levels of income and education.

Only 65% of patients reported that their healthcare team discussed issues related to financial toxicity, although most seemed to engage in shared decision-making. While there are no quick fixes to ensure that the burden of financial toxicity is minimized, a first step is to promote candid discussions between patients and physicians. Several pharmaceutical companies have co-pay and patient assistance programs, and healthcare teams should share such information with their patients.

The results of this study have been published in a white paper, which will be submitted to international medical conferences in order to disseminate the findings. Dissemination is important for all of our Patient FoRCe studies to ensure findings and implications are known and understood, with the ultimate goal of driving practice change so all people diagnosed with lung cancer receive optimal care.

LUNGevity Advocates for Access to Precision Medicine

Healthcare reform is a hot-button issue that has only grown more heated over the last several years. One of the more recent proposals coming from the Trump administration includes reforms to the Medicare system, which, if finalized, would negatively impact lung cancer patients.

The proposed reforms to the Medicare Part D program are of particular concern to people living with lung cancer. Medicare Part D helps Medicare beneficiaries pay for self-administered prescription drugs. In the current program, there are "six protected classes" of drugs that are required to be covered by all plans, including cancer medications. The proposed reform changes the current "six protected classes" policy. While it intends to lower drug prices, it does so by restricting what drugs a patient can use. If finalized, this reform could interfere with a doctor's ability to decide the best course of treatment for patients and even delay patients' access to lifesaving, innovative therapies.

Currently, there are twelve targeted therapy drugs that are FDA-approved for lung cancer covered under Medicare Part D that could be affected by any changes to the "six protected classes." LUNGevity strongly supports precision medicine and patient access to the right treatment at the right time. These reforms would be detrimental to patients by hindering this access.

In response to the proposed changes, LUNGevity participated in a multi-media ad campaign in January urging the Administration and Congress not to harm patients by limiting access to lifesaving medications through the proposed changes to the Medicare Part D "six protected classes" policy. The ad appeared in print and online editions of The Washington Post, The New York Times, The Hill, Roll Call, and Politico. LUNGevity also participated in an Online Day of Action on January 23; we partnered with other organizations in a coordinated social media campaign urging the Administration and Congress not to proceed with the

proposed changes to the six protected classes. Most recently, on March 28, LUNGevity participated in an advocacy day on Capitol Hill with 22 other organizations, urging lawmakers to protect the six protected classes.

We will continue to work with policymakers and other stakeholders to ensure that all people diagnosed with lung cancer have access to personalized, precision medicine and that care decisions are made between an individual, his or her provider, and their support network.

If you are interested in learning more about LUNGevity's public policy initiatives, please contact Kristen Santiago, Senior Director of Public Policy Initiatives, at ksantiago@LUNGevity.org, or check out the LUNGevity policy page at www.LUNGevity.org/public-policy to read our letters and see other ways we are advocating for patients. IMPACT REPORT

\$11.86 ROI

278

2.2

50 \$23.3

LUNGEVITY'S GROWTH AND IMPACT ON IMPROVING LUNG CANCER OUTCOMES

LUNGevity has published an impact report that showcases the advancements of the Foundation's research programs, patient services, major initiatives, fundraising achievements, marketing reach, and more, and shows how these accomplishments help drive progress in all areas of the lung cancer field.

The field of lung cancer research and patient care is advancing rapidly, and more people are now living well with lung cancer than ever before. LUNGevity is proud of its impact on improving outcomes for lung cancer patients through a better understanding of diagnosis, treatment, and quality of life, as well as through driving research and policy reforms.

Since its founding in 2001 by seven lung cancer survivors, LUNGevity has strived to identify and solve unmet needs in the lung cancer community. In 2001, this meant increasing awareness. In 2010, this meant funding the most impactful research. Today, this means tackling the most insuperable issues, from clinical trial access to ensuring patients receive optimal care. Every decision is made strategically to fill these unmet needs with our lung cancer community in mind.

LUNGevity is proud of the impact we have made, and we will continue to address the many challenges our community faces to drive change.

You can read the report and learn more about LUNGevity's impact at www.LUNGevity.org/about-us/our-impact.

Multi-Stakeholder Meetings for Biomarker Testing, *continued from page 1*

The Pan Tumor Roundtable focused on sharing best practices to increase awareness and education about biomarker testing, and included representatives from multiple cancer advocacy groups (including lung, ovarian, breast, pancreatic, and bile duct, among others). Each group had expertise in biomarker testing advocacy and shared experiences, allowing groups to benefit from each other, explore collaborations, and ultimately improve access to biomarker testing and precision medicine for their patients.

The Nursing and Nurse Navigator Roundtable was an important first formal meeting convened by LUNGevity with nurses and nurse navigators, who are responsible for critical conversations about biomarker testing with patients. They educate patients about the role of testing in finding the right treatment path, and are knowledgeable about the issues and barriers preventing patients from receiving the testing they need. The new insights arising from this discussion will help equip nurses/navigators with the information that they need to best support patients on issues around biomarker testing.

Both meetings were part of LUNGevity's Take Aim initiative, a multi-year, multistakeholder initiative to ensure that all people diagnosed with advanced stage non-small cell lung cancer have access to high-quality, comprehensive biomarker testing—a key component of precision medicine.

LUNCH & LEARN

in Washington, DC, builds community and spreads awareness about lung cancer

Lung cancer patients, caregivers, and advocates attended a LUNGevity Lunch & Learn at Johns Hopkins Sidney Kimmel Cancer Center at Sibley Memorial Hospital on March 29.



While LUNGevity has long held a National HOPE Summit (now International Lung Cancer Survivorship Conference) in Washington, DC, Sibley Lunch & Learn brings updates on living with lung cancer to a local audience.

Topics included information about targeted therapies in lung cancer; advances in radiation for lung cancer; an Ask the Lung Cancer Experts Q&A; a survivorship panel; and resources for patients and caregivers.

"The Lunch & Learn was an incredible opportunity to hear from experts about the fast-changing field of lung cancer treatment," Michelle M, a local caregiver, said. "Professionals provided excellent information about multidisciplinary care and support provided by the hospital as well as outside resources. It was also a great way to connect with other people dealing with lung cancer themselves and hear their stories."

LUNGevity Lunch & Learns take place across the country. Check out LUNGevity's website to see if there is an event near you.

Think your community would benefit from more lung cancer education? Reach out to Katie Brown, Vice President of Support & Survivorship, at kbrown@ LUNGevity.org to find out how to bring a LUNGevity Lunch & Learn to your local institution.

IN LUNG CANCER RESEARCH

advances

Highlights of the AACR 2019 Annual Meeting

INTEGRATIVE CANCER SCIENCE . GLOBAL IMPACT . INDIVIDUALIZED PATIENT CARE

The annual AACR meeting is the largest global gathering of basic cancer researchers, attended by over 23,000 attendees. The meeting aims to answer the fundamental question: How can we truly build upon our knowledge of basic science to impact patient care? Below is a summary of some of the key discoveries:

As *immunotherapy* becomes more mainstream, we are learning more about which populations benefit from it. Research from LUNGevity Scientific Advisory Board (SAB) member Dr. John Heymach's group at MD Anderson shows that mutations in a gene called LKB1/STK11 predict which patients may respond to immunotherapy. The group had previously shown that lung cancers with both KRAS and LKB1/STK11 mutations do not respond well to immunotherapy. Building on these findings, the team presented data on mutations in the LKB1/STK11 gene that predict which patients will respond to chemotherapy-immunotherapy combinations. New research presented shows that tumor mutational burden, or TMB (the total number of mutations found in the DNA of cancer cells), is emerging as a possible predictor of response in patients who have received either monotherapy or combination immunotherapy (anti-PD-L1 and anti-CTLA4 immunotherapies) in the 1st-line setting. New data also show that chemotherapyimmunotherapy combinations may provide benefit to patients with liver or brain metastases whose cancers do not have any targetable mutations; these patients have had limited treatment options.

Targeted therapies presentations included ones by Dr. Alice Shaw and Dr. Lecia Seguist, both from Harvard Medical School and Massachusetts General Hospital Cancer Center and both members of LUNGevity's SAB, on what's next for ALK and EGFR targeted therapies. ALK-positive lung cancer patients with access to 3rd-generation ALK therapies inevitably find their cancer recurs as cancer cells find ways to escape the effects of these therapies. Comprehensive biomarker testing of resistant tumors has helped us understand that cancer cells outsmart ALK inhibitors by developing additional mutations in the ALK gene or switching on other pathways. Now scientists are working to develop 4th-generation inhibitors that block these new mutations and are testing new combinations of drugs that can block these new pathways. A new drug, savolitinib, is showing promise in EGFR-positive lung cancer patients who have progressed on EGFR-blocking drugs. Savolitinib works by blocking the MET gene that is often turned on in cells treated with EGFR



Lung cancer patients and advocates at the AACR meeting; left to right: Jill Hamer-Wilson, Jill Feldman, Renay Caldwell, Rhonda Meckstroth, and Chris Draft

tyrosine kinase inhibitors. Around 25% of patients who progress on drugs such as osimertinib may have changes in the MET gene. We are also seeing progress in treatment development for other mutations, such as ROS1. The current standard of care for ROS1, crizotinib, does not enter the brain. Newer drugs, such as entrectinib, are showing promise in ROS1 patients who have never received a treatment or have progressed on crizotinib. Entrectinib is effective in patients with brain metastases.

Liquid biopsies, non-invasive blood tests that check for the presence of cancer DNA or cancer cells in the blood, are also seeing progress. They are being used to check for the presence of actionable mutations when tissue biopsies are not an option. We saw data from a clinical trial designed to check if tissue and liquid biopsies are comparable. Preliminary results indicate that liquid biopsies correctly detect mutations, such as EGFR and ALK, for which drugs exists. These findings establish that liquid biopsies may be accurate enough to decide treatment for patients with metastatic non-small cell lung cancer.

Importantly, the meeting included many **patient-founded and patient-driven oncogene-specific** group presentations. The EGFR Resisters and ALK Positive presented how their groups are driving research by educating patients, informing clinicians and researchers, and helping identify unmet needs specific to their communities. LUNGevity anticipates these groups playing more and more of a central role in lung cancer research, and we are proud to partner with them to accelerate progress.

advances

Intercepting and Treating Early-Stage Lung Cancer

Because lung cancer develops over time, researchers believe there is an opportunity to intercept it; that is, either catch precancerous cells and block them from turning into cancer cells in the first place or catch lung cancer in its earliest stages when it is most treatable.

LUNGevity Foundation has had a strong focus on early detection for over a decade. In 2017, LUNGevity teamed up with Stand Up To Cancer and the American Lung Association (ALA) to fund two lung cancer interception teams: the Lung Cancer Interception Dream Team and the Lung Cancer Interception Translational Research Team. The grants, totaling \$7 million over four years, went to teams of outstanding scientists with a profound desire to improve outcomes for lung cancer patients.

Today, these research projects are making exceptional progress in helping us understand, diagnose, and treat early-stage lung cancer.

Intercept Lung Cancer Through Immune, Imaging, & Molecular Evaluation (InTIME)

The InTime dream team is a vast collaboration of research laboratories spanning the United States and reaching as far as London, England. The goal of the team is to bring innovative changes and improvements to the detection and treatment of early-stage lung cancer.

"Less than 50% of lung cancers are caught early when they are the most treatable," explains Steven Dubinett, MD, Associate Vice Chancellor for Research at UCLA, an expert in the field of lung cancer immunology, and a member of LUNGevity's Scientific Advisory Board. "We are making major strides to change that... This is one of the most exciting collaborations that we have ever participated in."

The Dream Team is taking a multi-part approach to impact every aspect of care for early-stage lung cancer, including deepening our understanding of lung cancer origins, developing tests to detect early-stage lung cancer, and enhancing pre-and post-surgery treatment regimens.

This effort is co-led by Dr. Dubinett and Avrum Spira, MD, Professor of Medicine, Pathology and Bioinformatics at Boston University, a world-renowned genomics and bioinformatics researcher specializing in lung cancer, and a member of LUNGevity's Scientific Advisory Board.

"We saw this as an opportunity to work with the lung cancer nonprofit community to aim for transformative results. Having SU2C, LUNGevity, and ALA provide a collaborative platform to bring all of these leading researchers together to focus attention on the earliest forms of lung cancer is an unparalleled event in our field," notes Dr. Dubinett. "With such creative and experienced individuals working cooperatively to move the dial on lung cancer prevention and early detection, I am hopeful that ground-breaking developments are on the horizon for lung cancer patients and their families."

Lung Cancer Inception Assay (LCIA)

The Lung Cancer Interception Assay (LCIA) translational research team is working to develop better ways to detect lung cancer earlier. Although low-dose CT (LDCT) scans have proven effective for detecting lung cancer, less than 5% of patients who should be screened for lung cancer are actually getting screened. In addition, among those who are screened, there is a high false-positive rate.

Lecia Sequist, MD, MPH, an attending physician at Massachusetts General Hospital, an associate professor at Harvard Medical School, and a member of LUNGevity's Scientific Advisory Board, wants to develop a companion blood test for the LDCT scans to reduce the false-positive rate.

"It's extremely frustrating that we don't have the technology to find lung cancer earlier in the majority of patients," says Dr. Sequist. "If we really want to save more lives from lung cancer, we have to exponentially improve our diagnostics."

Dr. Sequist brought together her team of lung cancer researchers at MGH to design blood sample collection procedures and to oversee blood sample collection and usage. With the patient blood samples now collected, the research laboratories of the team's collaborators have been working to identify the best ways to test for early-stage lung cancer.

Max Diehn, MD, PhD, assistant professor of radiation oncology at Stanford University, is lending his expertise in detecting circulating tumor DNA fragments, or ctDNA, in patients' blood samples. So far, these results look promising, and the blood test seems sensitive enough to distinguish ctDNA in blood samples from patients with and without early-stage lung cancer.

Wilhelm Haas, PhD, director of the Proteomics Laboratory at the MGH Cancer Center, is a pioneer in the field of high-throughput proteomics. His laboratory is collaborating with Dr. Sequist to develop a blood test to detect proteins from early-stage lung cancer cells. This work is also very promising, as it demonstrates a low level of false-positive results.

The progress of these multidisciplinary teams reinforces the value of collaboration for impactful science.

advances

HIGHLIGHTS OF THE

2019 Small Cell Lung Cancer Meeting

The biannual Small Cell Lung Cancer (SCLC) Meeting convened by the International Association for the Study of Lung Cancer (IASLC) at Memorial Sloane Kettering in New York City is dedicated to providing an update on pre-clinical and clinical progress made in this specific subtype of lung cancer. Identified as a unique form of lung cancer in 1959, SCLC comprises 15% of all diagnosed cases of lung cancer. SCLC usually responds to initial chemotherapy; however, it inevitably becomes resistant to the chemotherapy and progresses. Also, unlike targetable mutations, such as EGFR and ALK, seen in non-small cell lung cancer (NSCLC), most molecular changes seen in small cell lung cancer are seen in genes such as RB1 and TP53, which are difficult to target. For a long time, not much progress had been made in our understanding of this subtype of lung cancer. In 2012, SCLC cancer was designated as recalcitrant (hard-to-treat) cancer by the National Cancer Institute. Also, the first genome sequencing efforts for SCLC were initiated in 2012.



At this meeting, 2016 Career Development Awardee **Dr. Jonathan Lehman** presented research on a new technology his laboratory is using to understand how SCLC cells escape the effects of chemotherapy. This technology, called CyTOF, enables researchers to study SCLC cells before and after they have been treated with chemotherapy—to pinpoint how SCLC cells

Dr. Jonathan Lehman

change and how new types of SCLC cells appear as a mechanism to escape the effects of chemotherapy. His laboratory has shown that certain types of SCLC cells can stay behind after chemotherapy. These "persistent" cells then grow and are responsible

for the tumor coming back. In addition, 2014 Targeted Therapeutics Awardee **Dr. Julien Sage** presented research aimed at identifying how SCLC cells metastasize. His team has found that SCLC cells adopt the behavior of neurons (nerve cells) to move around and metastasize. This research is especially important, given that most patients with SCLC present with metastatic disease at diagnosis.



Dr. Julien Sage



Dr. Charles Rudin

It is becoming increasingly apparent that, like NSCLC, SCLC can also be divided into other subtypes based on unique **biomarkers**. Several laboratories, including that of LUNGevity's Scientific Advisory Board Chair, **Dr. Charles Rudin**, have shown that SCLC cells produce three proteins, ASCL1, NEUROD, and POU2F3, whose expression is mutually exclusive: SCLC

cells mostly produce one of these three proteins or none at all. Based on these findings, SCLC can be divided into four subtypes: ASCL1-positive, NEUROD-positive, POU2F3-positive, and "triple-negative." These four subtypes have unique biology that in turn suggests that they may respond to treatments differently. We have also made significant progress in identifying biomarkers that not only predict response, but may also help in identifying and imaging SCLC. DLL3 is one such biomarker. It is produced in high amounts by SCLC cells and coats the outside of the cells. 2014 Career Development Awardee **Dr. John**



Dr. John Poirier

Poirier presented results that show that a new drug, Rova-T, that specifically attaches to DLL3 may also be used to image SCLC in mouse models. His team will initiate a clinical trial to test this imaging approach in SCLC patients.



Certain classes of **targeted therapies** also continue to show promise for SCLC. Drugs that block the DNA damage response (DDR-blocking drugs), such as PARP inhibitors, comprise one such class of drugs. 2015 Targeted Therapeutics Awardee **Dr. Lauren Byers'** laboratory has demonstrated that PARP inhibitors used in combination with immunotherapy may improve

Dr. Lauren Byers

the effects of immunotherapy in mouse models of SCLC. These encouraging data suggest that clinical trials testing these combinations may soon be available. In addition, PARP inhibitors combined with chemotherapy drugs, such as temozolomide, or with radiotherapy are continuing to show promise in SCLC patients who have progressed on first-line chemotherapy. **Immunotherapy** continues to be tested in SCLC—both as a first-line treatment option and also for patients who have progressed on first-line chemotherapy. A first-line immunotherapy (atezolizumab)-chemotherapy combination was recently approved by the U.S. Food and Drug Administration. This combination works for a small subset of SCLC patients. Discussions at this meeting suggest that two areas of intense research are how best to combine immunotherapy and which **biomarkers** would predict which SCLC patients will respond.

Finally, researchers are developing **liquid biopsy** technologies for SCLC. Though still in very early stages of research, liquid biopsies will be especially helpful because small amounts of biopsy tissue are typically obtained from SCLC patients. Also, liquid biopsies will be useful in understanding how SCLC responds to treatment and more importantly, how SCLC cells evolve with time—to better understand how these cells escape the effects of chemotherapy and other treatment approaches.

As we continue through the second golden age of discoveries in SCLC, we are enthusiastic about new discoveries in our understanding of the biology of the disease that translate into better technologies and therapies for detecting and treating it.

LUNG CANCER IN THE NEWS

"This is an exciting time in lung cancer research. While lung cancer remains a difficult diagnosis, the advancements and innovation in the field today are bringing hope to lung cancer patients. We're seeing a lot of biological insights being translated into improved outcomes for patients."

DR. UPAL BASU ROY, Senior Director of Research at LUNGevity

Lung-MAP expands participation eligibility to all non-small cell lung cancer patients

Lung-MAP (short for Lung Cancer Master Protocol) is a precision medicine clinical trial in lung cancer that began in 2014. It is supported by a unique partnership between the National Cancer Institute (NCI), Foundation of the National Institute of Health (FNIH), pharmaceutical companies, and lung cancer advocacy and other organizations. Lung-MAP is significant because it uses a unique clinical trial design called a "master protocol." This trial design provides more flexibility and efficiency and potentially hastens the development of new precision treatments. The design allows new treatments to be easily incorporated into the ongoing trial rather than each new treatment necessitating a new trial. Lung-MAP is offered at more than 650 medical centers and community hospitals around the country, making it possible for close to 2,000 patients to join the trial since its start.

Patients who enroll in Lung-MAP receive comprehensive biomarker testing to determine whether they have a mutation that matches a treatment being tested. If there isn't a match, patients are able to choose to receive an immunotherapy drug being tested.

When Lung-MAP launched in 2014, only patients with advancedstage squamous cell lung cancer were eligible. In January 2019, in order to reach more patients with potentially life-extending treatments, Lung-MAP opened eligibility to include *all* advanced stage non-small cell lung cancer patients. New immunotherapy treatments will be added for testing. For more information about Lung-MAP and about whether you might be eligible for the trial, ask your healthcare team and go to www.lung-map.org.

FDA approves atezolizumab (Tecentriq[®]) for extensive-stage small cell lung cancer in March 2019

The US Food and Drug Administration (FDA) recently approved atezolizumab (Tecentriq®), an immunotherapy drug, in combination with the chemotherapy drugs carboplatin (Paraplatin®) and etoposide (Etopophos®) for the first-line (initial) treatment of adult patients with extensive-stage (metastatic) small cell lung cancer. While this is the second immunotherapy drug approved for small cell lung cancer, the first, nivolumab (Opdivo®), is approved only for small cell lung cancer that has progressed after previous treatments.

Small cell lung cancer, which accounts for about 15% of all lung cancer diagnoses, is a highly aggressive, fast-growing lung cancer, and about two-third of patients are not diagnosed until after the disease has become metastatic. The approval of atezolizumab (Tecentriq*) is highly significant; small cell lung cancer has had fewer options for treatment that non-small cell lung cancer. There are currently no approved targeted therapies for small cell lung cancer, for example, although targetable gene mutations have been identified and are being studied.

Approval for atezolizumab (Tecentriq[®]) was based on the results of the IMPower133 clinical trial, in which the one-year overall survival rate was higher among those patients who received this drug along with the chemotherapy than among those who received a placebo along with the chemotherapy drugs.

The first "tissue agnostic" treatment for lung cancer has been approved by the FDA

In November 2018, larotrectinib (Vitrakvi[®]) was given accelerated approval by the FDA for patients with solid tumors that have a neurotrophic receptor tyrosine kinase (NTRK) gene mutation. This approval is "tissue agnostic," meaning that the treatment is based on the presence of the mutation rather than on where in the body the tumor originated. Lung cancer is a solid tumor that can be driven by the NTRK1 mutation, so lung cancer patients are among those who may use this targeted treatment. This is the first tissue agnostic treatment for lung cancer.

NTRK1 is a rare mutation, found in only about 3% of lung cancer patients, and larotrectinib (Vitrakvi[®]) is the first treatment that specifically targets it. NTRK1 is the fifth mutation for which lung cancer patients have an FDA-approved targeted treatment. The others are EGFR, ALK, ROS1, and BRAF V600E.

Note that the approval of larotrectinib (Vitrakvi*) is "accelerated approval." This is an approval that the FDA offers for earlier approval of drugs that treat serious conditions and that fill an unmet medical need. Additional studies by the pharmaceutical company that developed the drug are still required to confirm that there is, in fact, a clinical benefit. Regular approval is given if the drug does provide the benefit.



1) Dr. Charles Rudin, Chair of LUNGevity's Scientific Advisory Board and Face of Hope honoree, at the Celebration of Hope Gala, with board member and Gala Chair Lynne Doughtie and LUNGevity Chairman of Board Alexander Stern **2**) Andrea Ferris, President and CEO of LUNGevity, delivering remarks at the Celebration of Hope Gala **3**) Rosemary and James Marquardt, Dinner Chairs of the Celebration of Hope Gala **4**) Lung cancer survivor advocate Amanda Kouri with Celebration of Hope Gala emcee and WNBC weathercaster Dave Price **5**) Lung cancer survivors at the Celebration of Hope Gala **6**) Attendees of the Celebration of Hope Gala participating in the annual Saving Lives auction

Celebration of Hope Gala

The 6th annual Celebration of Hope Gala in NYC in November 2018, chaired by LUNGevity board member Lynne Doughtie, CEO of KPMG, was a great success. Leaders of business, philanthropy, and science gathered to raise funds for LUNGevity's research, education, and support programs.

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 2018 NYC Gala included Boehringer Ingelheim Pharmaceuticals, Inc. (Hope Award for Corporate Leadership) and Charles Rudin, MD, PhD (Face of Hope Award). Dr. Rudin is chair of the LUNGevity Scientific Advisory Board and professor and chief, Thoracic Oncology Service, at Memorial Sloan Kettering Cancer Center. Attendees included 25 survivors and 15 doctors and researchers, as well as guests representing the gala and national sponsors who supported the event.

With the help of returning emcee Dave Price, weather anchor for NBC 4 New York, survivor Amanda Kouri, and a professional auctioneer, LUNGevity raised the highest amount to date for a gala appeal.

New Patient Education Booklets Available

LUNGevity has added new booklets as part of its patient education series to help people affected by lung cancer better navigate the disease.

The new titles include Chemotherapy and individual booklets on Stages I-IV for non-small cell lung cancer (NSCLC). All booklets in the series are available in print and as downloadable PDFs.

Check out www.LUNGevity.org/booklets to read and download our entire educational series.





Team LUNGevity Expands to Include TCS New York City Marathon!

Team LUNGevity, LUNGevity's endurance sports program, now has entries to the TCS New York City Marathon, the largest marathon in the world! If you've always wanted to participate in this world-renowned event, you can do so while raising money for those affected by lung cancer.

This year's marathon will be on November 3, and the race is a qualifier for the prestigious Boston Marathon.

Team LUNGevity is expanding! This year, we expect the team to grow to over 90 runners, who will have the choice to run one of five official runs or a DIY event.

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 endurance events across the US and around the world, to help improve outcomes for lung cancer patients.

Research saves lives.

Make a donation today to support LUNGevity's research efforts to change how people live with lung cancer.

www.LUNGevity.org

Emily Daniels lung cancer survivor Golden, CO

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Nominate Someone for LUNGevity Spotlight!

LUNGevity Spotlight, LUNGevity's newest blog, highlights people in our community who are making a difference for those affected by lung cancer. We hope that these stories of patients, caregivers, volunteers, and fundraisers will inspire and encourage many more to get involved and help people live better with lung cancer.

Do you know someone in the lung cancer community whom you think should be featured? You can nominate that person on the LUNGevity website at www.LUNGevity.org/spotlight

Check out this highlight from an interview with a recent Spotlight nominee, survivor James Hiter, founder of Streak for a Cure.

What was the biggest unexpected change in your life after your diagnosis?

"While the decision to leave a 25-year career as a financial services executive was difficult, it was the right one for my family and me. The biggest intangible change impacted how I prioritized my life, attitude and activities. We have done more lung cancer advocacy, welcomed a 17-year old foster daughter into our home and spent more time with family."



Read more about James's journey at www.LUNGevity.org/jameshiter.

Finding Community and Purpose through Breathe Deep Events



Lauren Humphries and her fiancé Ben Bromley-Coolidge

BY LAUREN HUMPHRIES, LUNGevity's Senior Manager of Community Engagement The night my mom called to tell me that my uncle Keith had been diagnosed with Stage IV lung cancer, I experienced a sinking feeling in my stomach. My mind raced through a series of questions before finally settling on, "How can we help?" Our family wanted to make sure that Keith and his wife and children knew that they didn't have to face this alone.

By an incredible stroke of luck, we found out that there was going to be a walk in Oriole Park at Camden Yards to raise lung cancer awareness and funds for LUNGevity Foundation. We created a team that would fill half a section in the iconic green stands. The walk was being held in honor of Monica Pence Barlow, the Orioles public relations director, who was battling lung cancer.

When Monica stood on the dugout to talk about her diagnosis and treatment and the importance of research, it was the first time that Keith didn't feel alone. Monica was the first person he'd ever met since being diagnosed who was also ALK-positive. Keith knew he had his family and friends behind him, but he didn't have anyone to talk to who completely understood what he was going through. Suddenly, in Monica, he had that person. Keith wasn't the only one to make a positive connection that day. I met the founder of Breathe Deep Baltimore and several members of the committee. They were passionate volunteers, who had all been personally impacted by lung cancer. Like me, they were determined to raise lung cancer awareness and funds for research and support. The Breathe Deep program gave us a way to channel our passion.

2019 will mark my family's seventh year participating in Breathe Deep Baltimore while we celebrate eight years of survivorship for Keith. It will also mark five years for me as a full-time LUNGevity employee. One of my personal and professional goals is to try to help expedite the process for people newly diagnosed to connect with LUNGevity. I think about what a difference it could have made if my family had known about LUNGevity right away and if Keith had been able to connect with other people living with lung cancer through Breathe Deep, the LifeLine Support Program, the Lung Cancer Support Community, a HOPE Summit conference, or any of LUNGevity's many other programs to support patients.

Breathe Deep is an excellent gateway to these other programs and a great way to help raise awareness and funds for lung cancer while building community. I encourage you to find a Breathe Deep event near you to see how impactful these events can be!

LUNGevity Fundraisers Get Creative to Raise Money for Lung Cancer

PEOPLE IN THE LUNGEVITY COMMUNITY FIND ALL SORTS OF FUN WAYS TO FUNDRAISE FOR THE FOUNDATION

Jose Hernandez is partnering with motorcycle club Iron Order in June to lead the fourth annual memorial motorcycle ride for his father, Jorge A. Hernandez, through North Carolina. They raffled off a 1971 Harley and held several other fundraisers leading up to the ride, all benefiting LUNGevity.

Stephanie Flinn challenged her friends and families to a virtual burpee-a-thon (a burpee is a squat thrust!) from her deployment in the Middle East. She was able to honor a friend who passed away, all while doing burpees and raising funds to support lung cancer.

Tony Negro from New Jersey hosted his retirement party in honor of LUNGevity! He raised almost \$10,000.

A group of doctors in September will host a basketball game between doctors and attendees of a major medical conference to raise money for LUNGevity!

There are so many ways to get involved! You can use your imagination to create your own event benefiting LUNGevity and lung cancer research, support, and education through LUNGevity's DIY event program. These events range from sports and fitness to music to dining and even a wildly successful lemonade stand.

Those new to event planning shouldn't worry. Dedicated LUNGevity staff can help guide you to a successful event day with online tools to plan and manage a fundraiser.

Find out how you can organize your own DIY event at www.LUNGevity.org/events/ create-your-own-event.



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JOIN US AT THESE FUN AND INSPIRING **LUNG**EVITY SPRING AND SUMMER EVENTS

May 18	Breathe Deep South Lyon	South Lyon, MI
May 19	Chicago Spring Half Marathon & 10K	Chicago, IL
June 1	Breathe Deep Blue Ridge Concert	Blue Ridge, GA
June 1	Breathe Deep Michigan	Birmingham, MI
June 9	Breathe Deep Toledo	Toledo, OH
June 22	Breathe Deep Kankakee	Kankakee, IL
June 23	Breathe Deep NEPA	Wilkes-Barre, PA
Sep 8	Breathe Deep DuPage	Naperville, IL
Sep 21	Breathe Deep Seattle	Seattle, WA
Sep 21	Breathe Deep Bucks County	Southampton, PA
Sep 22	Breathe Deep Albany	Albany, NY
Sep 22	Breathe Deep Baltimore	Baltimore, MD
Sep 28	Breathe Deep Amador	Amador County, CA
Sep 29	Chicago Half Marathon & 5K	Chicago, IL

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



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