No One Missed
NATIONAL CAMPAIGN SEEKS TO RAISE AWARENESS OF BIOMARKER TESTING

According to the American Cancer Society's 2021 Statistics Report, there has been a 50% decrease in cancer deaths over the past five years due in large part to advances in new lung cancer therapies, particularly those targeted to specific biomarkers.

LUNGevity has long been active in promoting comprehensive biomarker testing for all patients diagnosed with advanced stage non-small cell lung cancer (NSCLC); ensuring that a patient gets matched to the right treatment at the right time, based on their biomarker status.

The No One Missed campaign—with a tagline of Know your Biomarkers. Know your Options—was launched in April to educate people with NSCLC on the importance of comprehensive biomarker testing in receiving a fully-informed diagnosis for the appropriate treatment. This multi-year, large-scale campaign is aimed at reaching all people diagnosed with NSCLC, including medically vulnerable populations (such as ethnic and racial minorities, rural communities, veterans, and older adults).

A dedicated section of the LUNGevity website provides easy-to-understand tools to empower both patients and caregivers to request comprehensive biomarker testing from their healthcare team at the time of initial diagnosis, recurrence, or progression. A three-step process (Talk. Test. Treat.), patient stories, video, and downloadable materials help a patient ask their doctor about biomarker testing.

No One Missed is a uniquely community-led campaign. LUNGevity is joined by patient groups, medical professional societies such as AONN and IASLC, and industry partners to spread the messaging. Support for No One Missed is provided by founding partner AstraZeneca; founding members Amgen and Genentech; supporting member Pfizer; members AbbVie, Daiichi-Sankyo, Merck, Regeneron, Sanofi Genzyme, Takeda Oncology and ThermoFisher; and supporters EMD Serono, Exact Sciences, Mirati Therapeutics, NeoGenomics, Novartis, and Oncocyte.

continued on page 3
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A monthly donation to LUNGevity brings hope to the lung cancer community and their loved ones by funding lifesaving research and patient programs.

To make a gift, use the QR code to connect directly or go to LUNGevity.org/SubscribeToEndLC

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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.
Family Reach Can Help Families Manage the High Cost of Cancer Care

The financial challenges that accompany a cancer diagnosis can be overwhelming for patients and their families. Often, patients resort to changing their medical care to save money for household essentials.

A new partnership announced by LUNGevity Foundation and Family Reach aims to relieve financial anxiety and create a realistic plan for the potential high cost of care. The collaboration will give lung cancer families access to Family Reach’s solutions within its Financial Treatment Program, including education, resource navigation, and budget planning.

As part of its Financial Treatment Program, applicants will receive the Family Reach Financial Guidebook for Cancer, and be matched with a Certified Financial Planner offering pro-bono consulting and resource navigation, including debt consolidation, in-kind support for transportation, housing counseling, and food insecurities. The program is being funded by Amgen as a corporate sponsor.

“We’re excited to be working with Family Reach to help families manage the financial burden of a lung cancer diagnosis,” says Andrea Ferris, President and CEO of LUNGevity Foundation. “For over 20 years, Family Reach has provided much-needed assistance to families facing the economic strain of cancer treatment. We know this partnership will improve the lives of many with their lung cancer journey.”

Patients and their families looking to access Family Reach’s portfolio of services should apply at www.LUNGevity.org/familyreach.

No One Missed

continued from page 1

The campaign has an informative and engaging website that provides resources to patients and their caregivers to support their biomarker testing process. NoOneMissed.org includes the steps to take to get comprehensive biomarker testing, patient stories, and downloadable materials with information on what biomarker testing is, tips to help facilitate a conversation about testing with your healthcare provider, and how to read your report.

Visit NoOneMissed.org to learn the facts about comprehensive biomarker testing and why it is so important for anyone diagnosed with NSCLC.
Amy C. Moore, PhD, Vice President of Global Engagement and Patient Partnerships

Dr. Moore will be responsible for growing and engaging LUNGevity’s patient communities globally, while also building relationships with professional societies around the world. Additionally, she will take the lead on some of LUNGevity’s educational initiatives, including the organization’s COVID-19 programming, and will be integral to LUNGevity’s clinical trial transformation work. As an active member of the Science Team, she will also take the lead for state-based policy directives.

Before joining LUNGevity, Amy served at the GO2 Foundation for Lung Cancer as the Director of Science and Research, where she oversaw the foundation’s portfolio of scientific programs. During her tenure, Moore facilitated new research initiatives and collaborations and vetted new technologies and partnerships for GO2 Foundation’s clinical trials research arm, the Addario Lung Cancer Medical Institute (ALCMI). She also served as primary liaison with oncogene-driven lung cancer patient groups.

As a trained virologist and cancer researcher with extensive experience in academia and over a decade in the nonprofit sector leading large research initiatives, Dr. Moore has published a number of peer-reviewed papers on a diverse range of topics from virology to cancer, including biomarker testing in NSCLC. She studied molecular mechanisms of acute leukemia development.

Arif J. Vega, PhD, Director of Equity, Diversity, & Inclusion — Engagement and Outreach

Dr. Vega comes to LUNGevity with a distinguished 26-year career in healthcare, where he has developed, implemented, and managed programs that focused on the intersection of representation, access, and HIV/HCV care. Most recently, as the Senior Administrator for the Maryland Department of Health Office of Minority Health and Health Disparities, he created strategies to address medical care inequities within minority communities while managing CARES ACT grants totaling over $3.8 million.

Before his tenure at the Maryland Department of Health, Dr. Vega served as Senior Director of Diversity and HIV Medical Programs and Services for Mary’s Center, where he was instrumental in implementing strategy and embedding diversity, equity, service learning, and civic engagement within agency-wide policy and training curriculum.

In his new role, Dr. Vega will engage medically underserved populations with trusted stakeholders to gain community insights and deliver information, hope, and awareness for optimal lung cancer care. He will also work with legislators at the state and federal level (e.g., Black and Latinx Caucuses) to address issues relevant to access to quality lung cancer care throughout the care continuum for vulnerable communities.

Kristi M. Griffith, MSN, RN, CHPN, HON ONN-CG
Survivorship Navigator

A nurse navigator with over 30 years of oncology and palliative care experience, Griffith will serve as the first point of contact for patients and families that reach out to the Foundation for support. She will deliver patient support and comprehensive disease information to lung cancer patients and their families/caregivers along with additional resources to increase lung cancer knowledge and help eliminate barriers to timely and optimal care.

Previously, Griffith served as Director, Palliative Care Administration, at Baylor Medical Center before working as an Oncology Nurse Navigator at the Charles A. Sammons Cancer Center. Having served on various national boards and committees, including the Academy of Oncology Nurse and Patient Navigators (AONN+) and the National Board for Certification of Hospice Palliative Nurses, she currently serves on the national AONN+ Certification Exam Development Committee for Oncology Navigators.

Griffith received her Bachelor of Science in Nursing from The University of Texas at Arlington and later received her Master’s in Science of Nursing from The George Washington University.
Why Patient-Reported Data Matter

The multi-year study seeks to understand how patients with lung cancer experience their disease in terms of symptoms, treatments, side effects, and quality of life.

In September 2020, LUNGevity Foundation announced the launch of a new longitudinal study in collaboration with the U.S. Food and Drug Administration (FDA) Oncology Center of Excellence (OCE) titled Understanding the lung cancer Patient Experience in the Real-world setting (Project PEER).

The goal of Project PEER is to understand the lung cancer patient experience outside of the clinical trial setting. The information collected from the study will be used to explore patient experience patterns and compare them to those seen in clinical trials within the same population to understand unmet needs in treatment access and how patients undergo treatment sequencing in the real world. This information will be critical in driving changes in lung cancer reasearch, treatment and policy.

The project is using the EmpiraMed™ PRO Portal™ Software Platform which allows people to easily participate in Project PEER. Any patient or caregiver, anywhere in the world, can participate in this global study.

“In the last few years, science has progressed at an unprecedented rate as new categories of therapies have become available and the application of existing therapies has expanded,” says Dr. Upal Basu Roy, PhD, MPH, LUNGevity Executive Director of Research and team lead of Project PEER. “However, reasons for treatment discontinuation (side effects, progression, mechanisms of resistance, etc.) are not well documented beyond a clinical trial context. Similarly, how patients experience their disease in terms of symptoms of the disease, side effects of the therapies, and quality of life throughout their disease journey is unclear. We are very excited about this study to better understand these issues and, ultimately, help provide the best care possible to the lung cancer community.”

Project PEER is a global study and open to any English-speaking adult lung cancer patient or caregiver. You can find more information on Project PEER at the study website: https://www.studylc2.empiramed.org/pub/study/lc2

Project PEER is made possible by the following corporate sponsors: Gold Sponsor Amgen, Silver Sponsors Genentech, Takeda, AstraZeneca, G1 Therapeutics, Blueprint Medicines, Merck, Lilly, and Boehringer Ingelheim, and Bronze Sponsor Jazz Pharmaceuticals

How can we make policy, build protocols, offer treatment and therapies, and only focus on a select group? We must be inclusive in our approach to change disparities; these foundations we create will then allow us a treatment that is truly for “ALL.” All means All. I don’t want to lose another friend to Lung Cancer and for it to continue to be the number one cancer killer; this is why I participate in the Peer Project. So that voices like mine and voices like yours count.”

NICHELLE STIGGER,
lung cancer survivor and advocate, member of LUNGevity Board of Directors
Congratulations on your promotion! As the first Executive Director of Research for LUNGevity Foundation, what can you tell us about your role with the organization?

As Executive Director of Research, I am privileged that I get to wear three hats—the translational science research hat, the patient/caregiver education hat, and the patient-focused research hat—as well as work with a fantastic and passionate team. Together with this team, I manage our translational science research program that funds lung cancer research into early detection and treatment at outstanding academic institutions throughout the United States. I also lead the Foundation’s in-house patient-focused research center (Patient FoRCe), through which we run studies to understand the patient and caregiver experience and identify unmet needs in the community. I also oversee our patient and caregiver education program that includes a comprehensive and ever-evolving guide to lung cancer—Lung Cancer 101—on the LUNGevity website, and patient/caregiver education booklets.

One of the programs that you developed and launched is the Foundation’s Patient-Focused Research Center (Patient FoRCe). What can you share with us about the program’s growth since its introduction?

Our in-house research center was launched in 2017, a time when such a lung-cancer-specific center did not exist. For a long time, the research community depended on proxies to learn about patient needs—doctors were asked about patient preferences and desires. With new therapies starting to become available and patients living longer, we felt the need to develop a process to directly learn from patients. That was the guiding principle of Patient FoRCe—to systematically capture the patient voice through studies and then use the information to drive change in how we deliver healthcare. To date, we have finished eight projects, presented sixteen abstracts, and published five papers. I am incredibly proud of what we have been able to achieve through Patient FoRCe since its launch.

This year, LUNGevity Foundation is introducing three new translational and clinical research grants. What can you tell us about these opportunities, and why are you excited about them?

Over the years, LUNGevity Foundation has strategically invested in three research areas: early detection of lung cancer, lung cancer treatments, and, through our Career Development Award program, development of the next generation of leaders. The three new award programs—the VA Research Scholar Award, the Health Equity and Inclusiveness Junior Investigator Award, and the Health Equity and Inclusiveness Research Fellow Award—build on our highly successful Career Development Award program. Through these new awards, we hope to strategically expand the lung cancer research workforce.

Approximately 7,700 veterans are diagnosed with lung cancer each year. The VA Research Scholar Award is meant to support young investigators interested in addressing unmet needs specific to our veteran population.

Similarly, the two Health Equity and Inclusiveness Awards are meant to increase representation of minority researchers in the lung cancer workforce. Black men, for example, made up less than 3% of physicians in 2020, reminding us that we are really behind in terms of representation. It is well documented that bridging care-delivery gaps in underserved communities will require clinicians and researchers who understand the unique needs of these different communities. Therefore, increasing representation of minority researchers and doctors in the workforce will be critical in advancing our efforts toward health equity.

One of the programs that you oversee is the research grants provided through our partnerships with patient groups, such as the EGFR Resisters and ALK Positive. Why are these partnerships important to LUNGevity?

One of the most gratifying parts of my position is to be able to work with patient groups to help drive research projects that are meaningful to them. These groups recognize that traditional funding and research models found in federal funding bodies, such as the National Cancer Institute and the Department of Defense, are limited in their ability to foster research in unique lung cancer subtypes. Therefore, groups, such as the EGFR Resisters and ALK Positive, have taken matters into their own hands. They are challenging the status quo by not only fundraising, but also driving research projects specific to their type of lung cancer. These are truly patient-funded, patient-founded, and patient-driven partnerships.

continued on page 9
EGFR-positive lung cancer is a type of non-small cell lung cancer (NSCLC) that is caused by mutations in the EGFR gene. Such mutations are found in 10%-15% of non-small cell lung cancer patients in the US and 35% of patients in Asia. Currently, five different targeted therapies (tyrosine kinase inhibitors) are approved by the United States Food and Drug Administration (FDA) for the treatment of EGFR-positive lung cancer. Despite an initial response to these drugs, the cancer often comes back or spreads because the cells develop resistance to these drugs.

The EGFR Resisters are a global grassroots community of over 2,500+ patients and caregivers affected by EGFR-positive lung cancer and dedicated to changing EGFR-positive lung cancer into a manageable, chronic disease. In the last issue of Fresh Air, Ivy Elkins and Jill Feldman, co-founders of the EGFR Resisters, discussed the reasons for their research partnership with LUNGevity. These reasons include agreement about the urgency of funding impactful research as well as a strategic and thorough approach to translational research.

The EGFR Resisters and LUNGevity Foundation are delighted to announce the recipients of the first EGFR Resisters/LUNGevity Lung Cancer Research Awards. The two 2021 projects were selected from a set of stellar applications for research to improve outcomes of non-small cell lung cancer patients whose tumors have an EGFR mutation. With funds raised by the EGFR Resisters, these awards total $200,000 each over a two-year term.

Both awards focus on solutions to issues that render current treatments ineffective and answer an important question: **What’s next after treatment with osimertinib, the current standard of care used as the first treatment for EGFR-positive lung cancer?**

The 2021 EGFR Resisters/LUNGevity Foundation Awards have been presented to:

**Christine Lovly, MD, PhD**
Vanderbilt University Medical Center
**Targeting drug tolerant states + DNA damage to block osimertinib resistance**

With osimertinib’s utilization in the first-line setting, there are now no FDA-approved targeted therapy options for patients who develop osimertinib resistance. The majority of studies to date have focused on treating osimertinib resistance once the resistance has already developed and the patient has signs of tumor growth. Dr. Lovly’s team is developing up-front combination regimens that will block resistance before it emerges, similar to the use of combination anti-microbial therapies for treatment of patients with HIV. They will focus on analysis of Drug Tolerant Persistor Cells (DTPCs) — cells in a tumor that remain in the tumor that is seen on scans in the clinic, even after patients have had a partial response to osimertinib. Using cutting-edge cell biology techniques, Dr. Lovly and her team will study how these DTPCs remain in a cancer after treatment with osimertinib and how new combination treatments can remove these cells.

**Helena Yu, MD**
Memorial Sloan Kettering Cancer Center
**Molecular characterization of lineage plasticity**

Resistance of EGFR TKIs can happen through different pathways. One such pathway is known as histologic transformation, where treatment with an EGFR TKI leads to the NSCLC changing into small cell lung cancer (SCLC). SCLC transformation occurs in 3%-10% of EGFR TKI-resistant cases. Targeted therapies are ineffective, and no strategies are available to prevent or reverse transformation after it has occurred. Mutations in EGFR/TP53/ RB1-mutant lung cancers are associated with transformation, but additional, molecular changes must occur for transformation to happen. Dr. Yu and her team will use advanced molecular techniques to identify the mutations and cell signaling pathways that drive transformation to identify biomarkers that can be utilized to develop treatments to prevent and reverse transformation. Treatments will then be validated in their unique pre-clinical models, which can be rapidly translated into clinical trials, providing treatments for these aggressive cancers.

**With funds raised by the EGFR Resisters, these awards total $200,000 each over a two-year term.**
In the past few years, immunotherapies, or treatments that leverage the body's natural immune system to fight disease, have emerged as an exciting treatment option for advanced-stage lung cancer patients. While a small percentage of patients have ongoing, long-term success with immunotherapy, many patients who are treated with immunotherapy show only an initial response to treatment. T-cells are specialized immune cells involved recognizing and fighting cancer. The timing of the diminishing response may be correlated with T-cells not being activated effectively, also known as T-cell exhaustion.

In 2019, Dr. Bauml applied for and was awarded a Career Development Award from LUNGevity to fund this important clinical trial and the accompanying research that Dr. Bauml proposed. In addition to monitoring patient side effects and tumor sizes in this phase 2 clinical trial, Dr. Bauml is collecting tumor biopsy samples and blood samples for subsequent analysis. Using a laboratory technique called flow cytometry, Dr. Bauml and his team will be able to study the cellular receptors found on the T-cells in the patients' blood and within tumors at different stages of treatment. This will allow his team to gain a deep understanding of the interplay between the interferon pathway and immunotherapy.

Although enrollment for the trial was slow during the initial months of the COVID-19 pandemic, Dr. Bauml and his colleagues have already enrolled and treated 20 patients in the clinical trial. “The side effects from adding in the interferon inhibitor have been very mild,” notes Dr. Bauml. “No one has been hospitalized, and no one has asked to stop taking the medication.”

“The results have been very exciting. Our hope is that one of our next steps could be to continue this work in a phase 3 randomized clinical trial, but we have to wait and see what the final results reveal before moving forward.”

“The LUNGevity award has been transformative for my career,” he says. “I would not be able to conduct this clinical trial and do the important data analysis without it. I am particularly grateful for the opportunity to meet so many leaders in the lung cancer field. Their support and comments have been invaluable to my research.”

Part of Dr. Bauml’s research interest lies in promoting innovative clinical trials that quickly and safely translate knowledge gained from basic science laboratories into the clinic to help patients.

“My ultimate goal is to improve outcomes for patients with lung cancer. We still have a long way to go, but I am confident that by working together we can build a world where no one dies of lung cancer.”

JOSHUA BAUML, MD,
Assistant Professor of Medicine, Hospital of the University of Pennsylvania
Q&A with Upal Basu Roy

continued from page 6

The ALK Positive community has funded more than $2M in translational research in partnership with LUNGevity. The investment made by ALK Positive is the largest investment made to date by a lung cancer patient group. In addition, the EGFR Resisters have partnered with us on two projects. Project PRORITY is a real-world data-gathering study that aims to identify unmet needs unique to the EGFR community. The EGFR Resisters also just funded two translational research projects directed toward understanding how EGFR-positive lung cancer escapes targeted therapies and starts growing again.

Advocacy is a team sport. These strategic partnerships with patient groups are a testament to that.

What gives you hope when you think about the future of lung cancer care and research?

What gives me hope is the power of research in changing outcomes. When I started at LUNGevity Foundation in 2015, drugs targeting only two mutations in lung cancer were available. Immunotherapies weren’t approved yet. Since 2015, 20 new treatments have been approved. All of this has been possible because of research.

We are at a critical point where our understanding of the molecular biology of lung cancer is translating into action. Small cell lung cancer, a highly aggressive type of lung cancer that had not seen progress in the past two decades, finally has seen change in how we treat it. And then there is KRAS—the first mutation discovered in lung cancer, but very resistant to targeting. Scientists have finally cracked the KRAS nut. We will soon see drugs targeting a specific type of KRAS mutation. Of course, I do want to add that we cannot become complacent. We still have a long way to go. My dream, as a patient advocate and a scientist, is that we have a treatment option for every patient, so that no one is left behind.

KRAS mutation. Of course, I do want to see drugs targeting a specific type of lung cancer. As a patient advocate and a scientist, I will continue to press for innovation and change. We still have a long way to go, but I am hopeful that we will make progress.

The new program, part of LUNGevity’s Health Equity and Diversity Initiatives, recognizes community leaders who work to eradicate disparities in medical care.

Everyone deserves the opportunity to receive quality healthcare. However, for many medically underserved populations (such as those in rural communities, areas of lower socioeconomic opportunities, or racial or ethnic minorities), the overlap between structural barriers that patients face every day and significantly lowered health outcomes is impossible to ignore.

The job of bridging the gap caused by healthcare disparities falls to dedicated professionals who, through advocacy and targeted medical intervention, work to meet the needs of the most vulnerable. These are the practitioners, community activists, researchers, and patient advocates who toil at the intersection of medicine and social justice — often with little or no fanfare.

It is with these individuals in mind that LUNGevity Foundation created the Community Champions program. Part of the organization’s Health Equity and Diversity Initiatives, the program identifies health equity leaders in lung cancer who personify our stated mission of making an immediate impact on increasing the quality of life and survivorship for all people diagnosed with lung cancer.

Community Champions are selected based on the following criteria:

• Their work is focused on creating sustainable and impactful solutions to address lung cancer disparities and to drive health equity for populations that they serve

• They conduct programs, research, education, and policy change with deliberate insights and partnership with trusted community-based organizations and vulnerable communities

• They demonstrate leadership to ensure a diverse and inclusive healthcare workforce

LUNGevity named Karriem Watson, DHSc, MS, MPH, as the program’s first honoree for his dedication to addressing the needs of Chicago’s neighborhoods at risk for lung cancer.

“For us to move ahead as a society, it’s imperative that we begin the conversation on how safe and equal access to healthcare should be a right afforded to everyone. I’m glad organizations like LUNGevity are committed to inviting the discussion while providing a seat at the table for all who are interested.”

KARRIEM WATSON, DHSc, MS, MPH

Associate Director of Community Outreach and Engagement, University of Illinois Cancer Center; Research Assistant Professor, UIC School of Public Health

www.LUNGevity.org
LUNGEVITY INTRODUCES ITS

Health Equity Council to Address Health Disparities in Medically Vulnerable Communities

This February, LUNGevity Foundation convened its newly formed Health Equity Council. The group’s main objective is to guide the organization in its quest to make sure that all people diagnosed with or at risk for lung cancer have the same opportunity for best-case outcomes and treatment, irrespective of their geographic location, socioeconomic status, race, ethnicity, age, or marginalization in society.

HEALTH EQUITY COUNCIL MEMBERS

Sanket Agrawal
Amgen Oncology

Carla Berg, PhD, MBA, LP
George Washington Cancer Center
Milken Institute School of Public Health

Rickie Brawer, PhD
Sidney Kimmel Medical College,
Thomas Jefferson University Hospital,
Center for Urban Health

Cherie P. Erkmen, MD
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Lisa Cruz, MPA
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Colette McCoy
AstraZeneca

Narjust Duma, MD
University of Wisconsin-Madison

Marianne Gandee
Pfizer Oncology
LUNGeity’s Health Equity Council consists of a diverse mix of oncology researchers, community leaders, patient advocates, pharmaceutical company representatives, and doctors who work with high-risk areas. The members were selected for their expertise on a range of lung health topics as well as their lived experiences within their respective geographic/cultural communities. The council is key to the success of LUNGeity’s Health Equity and Diversity work. Overseen by the foundation’s Chief Health Equity and Diversity Officer, Jeanne Regnante, the program focuses on identifying key strategies to pinpoint and address lung cancer care disparities caused by social determinants of health.

The Health Equity Council is made possible through generous sponsorship from the following organizations: Amgen, AstraZeneca, Blueprint Medicines, Bristol Myers Squibb, Eli Lilly, Genentech, Johnson & Johnson, Merck & Co., Novartis, Pfizer, and Takeda.
Lunch & Learn

Lunch & Learn with LUNGevity events are informative, interactive community meetings held in partnership with medical centers across the country. Attendees can hear from lung cancer experts in their community and learn about support programs and resources in an informal setting. Each meeting includes sessions on lung cancer treatment options, advances in lung cancer research, tips on how to live well with cancer, and support resources for patients and caregivers.

For more information about the Lunch & Learn program, contact Katie Brown, Senior Vice President of Survivorship & Support, at hope@lungevity.org.