

fresh air

Volume 9, Issue 2

FALL 2020

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LUNGevity LAUNCHES

The Action Network



This October, LUNGevity Foundation launched the LUNGevity Action Network, a new initiative that strengthens lung cancer advocacy through tangible actions at many levels. The platform is designed to empower advocates to engage in awareness and policy actions to help drive change and improve the lives and outcomes of those affected by the disease.

Through **awareness-related actions**, members can help their community by sharing their personal stories, creating and posting important information on social media, and distributing educational materials locally to spread facts and information about lung cancer.

Through **policy-related actions**, members can make their voices heard on issues that affect the lung cancer community by taking actions such as writing their

congressmen, signing petitions, and commenting on new regulations.

Utilizing the Network, advocates can educate themselves on important issues before using the simple, accessible tools to make their individual and collective voices heard. Members will receive a roadmap on how best to have an impact, including specific actions based on their area of interest that help keep advocates motivated and on track to be successful.

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LUNGevity Goes Virtual

with our 2020 International Lung Cancer Survivorship Conference

The conference, now in its 10th year, welcomed 1,445 registrants from 38 countries with more than 1,000 first-time attendees. Dr. David Carbone, LUNGevity Scientific Advisory Board member and director of the James Thoracic Oncology Center at The Ohio State University Wexner Medical Center Comprehensive Cancer Center, kicked off this unique event with a moving keynote address. He was followed by an action-packed

two-day conference. Participants were connected with experts and leaders in over 30 specialized sessions, with such topics as navigating lung cancer in the VA, lung cancer care in the community setting, and lung cancer, COVID-19, and the African American community. Activities closed on Sunday with a dynamic event helmed by lung cancer advocate and former NFL player, Chris Draft.

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As we continue to adapt to life during the pandemic, LUNGevity is proud that our Translational Research program continues uninterrupted with the announcement of new research awards in both our Career Development program as well as through our collaboration with the ALK Positive patient group. We are also reimagining programs to deliver them to you in new ways.

Our support and survivorship programs are 100% virtual, with weekly "meet-ups," Lunch and Learns, and many additional activities. This year's International Lung Cancer Survivorship Conference, attended by 1,445 people from 38 countries, included 30 sessions and featured 50 experts from around the US. We invite you to experience the conference yourself by watching our taped sessions. Find them at <https://LUNGevity.org/ilcsc>, and register for our 2021 conference!

We are also proud to kick off Lung Cancer Awareness Month this November with the launch of an exciting new advocacy program. The LUNGevity Action Network has tools to help you be a successful advocate, whether you're interested in raising awareness in your community or helping to drive policy that affects the entire lung cancer community. We hope you'll sign up to stay connected and amplify your voice and impact.

To learn more and get involved for Lung Cancer Awareness Month, visit www.LUNGevity.org

Thank you for your continued support.

Andrea E. Ferris

LUNGevity'S MISSION

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

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Interview with Robert Winn, MD



Robert Winn, MD

LUNGevity Foundation Board Member and Director of Virginia Commonwealth University Massey Cancer Center.

Dr. Winn, a fierce advocate for health equity, joined the LUNGevity Board of Directors in June 2020. He recently spoke with Jeanne Regnante, LUNGevity's chief health equity officer, about his lung cancer advocacy, inequities in healthcare, and what gives him hope.

Dr. Winn, how do you define health equity for the patients we serve?

I think that there are three main components of health equity. First, equity is when I have access to not just care but high-quality care, regardless if I have \$10 in my pocket or \$100,000 in my bank account. That's one marker.

The second health-equity component means that not only do I have access to both health systems and treatment for my cancer, but also to those life-saving clinical trials that may be available. When we look at the diversity and equity around clinical trials, not every population has this kind of access.

The third component means that, as a community, we can impact the doctors who are treating patients — by asking questions, participating in clinical trials, and providing scientific data. Unfortunately, not every community group has the ability to sit at the table with researchers and clinicians. For me, access and health equity are a bit different. But it's based on a person's ability to influence the type of clinical trials, the standard of care, and the kind of research conducted. When everyone has the same opportunity to do that, we will have accomplished something great.

What specific health disparities need to be erased for people at risk of developing lung cancer or who have been diagnosed with lung cancer?

The one example that jumps out to me is the disparity gap in lung cancer screening. It's just not acceptable. We know that many of the at-risk populations carry the

heaviest burdens from lung cancer. It makes no sense that we don't have more strategies around reaching into these communities. Eradicating any disparities around screening means a lot to me.

I think Dr. Otis Brawley, distinguished professor of Oncology and Epidemiology at Johns Hopkins University, had it right when he said that typically when you advance new technologies you introduce disparities. And so, as we're introducing new technologies to cure or screen, we recognize that it gets into one community and not the other. So, how do we reduce these gaps? How do we all sit at the table so that we can have pragmatic and innovative ways of reducing disparities?

I think we know what the problem is. I think we even have strategies on how to fix the problem. We need to have the desire to confront the issue. If I had a magic wand, I would make that my wish that we have the political will and the intestinal fortitude to stick to some of these solutions to reduce some of these disparity issues. I think that it's going to take those unsung heroes and champions to keep chipping away at this.

Why is partnering with trusted community leaders a critical part of LUNGevity's health equity strategy?

It has become clear that advocacy starting from the community is the secret sauce to getting anything done. The reality is, as a healthcare provider or a researcher, I can come up with a lot of great ideas. But, if folks within the community don't trust or don't respect the information, it doesn't matter how wonderful our therapies are. We won't be able to have a positive impact.

It is important to remember that not everyone is science- or health-literate. The science community can fail to understand how to engage with the public. For example, with clinical trials, what are the trigger words that we need to know? If we talked about clinical trials as a continuum of care, we might get better traction.

We used to think of community outreach as putting up a flyer, setting up a tent, and talking to people about cancer. We now know that what is most efficient and effective is engagement. This means that not only are we giving information to the community, but we're also receiving valuable information from the community that helps us connect with their specific needs.

Why is LUNGevity positioned to address health equity in lung cancer?

I think the reason why LUNGevity is in a great position is because we have the right leadership. It starts there. We have leaders within LUNGevity who not only feel passionate around this issue, but are also dedicated to coming up with strategies and are committed to recruiting folks who have expertise around this issue.

Dr. Winn, what gives you hope for patients with lung cancer?

If I look at the overall cancer disparities from 1999 through 2020, the difference has been reduced dramatically from 30% to about 15%. In my lifetime, I've seen miracle drugs on the market that are giving people with lung cancer a new lease on life. When I started, scientists told us that other than the cisplatin-based chemotherapy, treatment was mostly prayer. We now have a whole lot more in our arsenal to be able to treat lung cancer.

LUNGEVITY WELCOMES

William “BJ” Jones, Michael Kolodziej, M.D, and Robert Winn, MD, to Foundation’s Board of Directors

LUNGEvity Foundation is proud to announce the appointment William “BJ” Jones, chief commercial officer, Migraine and Common Diseases at Biohaven Pharmaceuticals, Michael Kolodziej, M.D, senior advisor at ADVI Health, and Robert Winn, MD, director, Virginia Commonwealth University Massey Cancer Center, to its Board of Directors.

A pharmaceutical executive with two decades of commercial and neuroscience expertise in large pharmaceutical companies and small biotech firms, BJ Jones has held leadership roles of increasing responsibility at Takeda Pharmaceuticals, AstraZeneca, Bristol-Myers Squibb, Boehringer Ingelheim, and NitroMed. Before his stint in the pharmaceutical industry, he served in the U. S. Air Force and earned the rank of Major.

In his current role at ADVI Health, Michael Kolodziej provides support for innovative alternative payment programs, including the Oncology Care Model and private payer initiatives, on behalf of life science, payer, and provider organizations worldwide. Prior to ADVI, he joined Flatiron Health in July 2016 as national medical director,



William “BJ” Jones



Michael Kolodziej MD



Robert Winn, MD

Managed Care Strategy, where he applied the core tech and data capabilities of Flatiron to facilitate practice transformation and success in alternative payment models.

As director of VCU Massey Cancer Center, Robert Winn oversees a facility that conducts groundbreaking cancer research while offering high-quality education, training, and community outreach programs. An advocate of health equity in lung cancer; he has championed the expansion of access to high-quality, low-density CT (LDCT) screening among historically marginalized, high-risk populations. Currently, Robert is the only African American director of a National Cancer Institute-designated cancer center.

“We are thrilled to welcome BJ, Michael, and Robert as new directors to LUNGEvity’s board,” said LUNGEvity Foundation President and CEO Andrea Ferris. “They join LUNGEvity at an exciting time as we expand our programs to better improve outcomes for all people living with lung cancer. We have much to learn from these new members of the board, and we look forward to their contributions in the years to come.”

Bellinda King-Kallimanis, Ph.D, as Director of Patient-Focused Research



Bellinda King-Kallimanis, MD

LUNGEvity Foundation is pleased to welcome Bellinda King-Kallimanis, PhD, as its new director of patient-focused research, where she will be spearheading research studies conducted through Patient FoRce.

Before joining LUNGEvity, she worked at the US Food and Drug Administration Oncology Center of Excellence on the Patient-Focused Drug

Development team. There, Bellinda worked on the development and launch of Project Patient Voice, a resource for patients and caregivers, along with their healthcare providers to look at patient-reported symptom data collected from cancer clinical trials. Bellinda also has experience in industry and academia and has published over 60 peer-reviewed papers that cover disease areas like lung cancer, depression, cognitive impairment, and multiple sclerosis.

Bellinda received her Bachelor of Social Science and her Master of Science in Applied Statistics from Swinburne University of Technology in Melbourne, Australia, and her Ph.D. in psychometrics from the Academic Medical Center in Amsterdam, Netherlands.

Elizabeth Barksdale, PhD, New Director of Regulatory Affairs and Scientific Policy



Elizabeth (Libby) Barksdale, MD

LUNGEvity Foundation welcomes Elizabeth (Libby) Barksdale, PhD, as its new director of regulatory affairs and scientific policy.

In her new role, Libby will guide the development and execution of LUNGEvity’s regulatory affairs as well as the organization’s Scientific and Clinical Roundtable Initiative. She will also offer both research and scientific content for LUNGEvity’s

policy outreach while representing the organization with key audiences, such as associations, coalitions, regulators, industry leaders, and legislators.

Most recently, Libby served as the assistant director for regulatory science and policy at the American Association for Cancer Research (AACR), where she led efforts aimed at increasing understanding of the regulatory ecosystem and enhancing the development of oncology products. Before joining the AACR, she was with the Federation of American Societies for Experimental Biology (FASEB), where she focused on policies related to clinical research and biomedical research training.

Dr. Barksdale received her BS in biology from Hope College and a PhD in molecular medicine from The George Washington University. She sought out experiences in science policy while conducting postdoctoral research at the National Institute of Child Health and Human Development (NICHD).

advances

Why the EGFR Resisters is partnering with LUNGeivity



Ivy Elkins



Jill Feldman

The EGFR Resisters is a grassroots community of over 2,200 EGFR-positive lung cancer patients and caregivers from 70+ countries,

dedicated exclusively to improving outcomes for people with EGFR-positive lung cancer by changing EGFR-positive lung cancer into a manageable, chronic disease.

by Ivy Elkins and Jill Feldman, EGFR Resisters co-founders

The EGFR Resisters decided to partner with LUNGeivity to fund and support research for a number of reasons. Founded by seven lung cancer patients as the first organization in the country dedicated to funding lung cancer research, LUNGeivity understands the importance and urgency of funding the most promising innovative and impactful research. Their approach to translational research is strategic, and they understand that patients' preferences should be incorporated throughout the research process. We are aligned with LUNGeivity's thorough and fair approach to research and feel that by working together, we will be able to find the best possible scientifically sound project(s) to fund in order to transform the future for patients diagnosed with EGFR-positive lung cancer. By working with LUNGeivity, we have the advantages of using their tested process honed over many years to review proposals, involving a team approach that includes scientific experts, biostatisticians, and patient advocates.

The partnership is unique in that the research is patient-funded and patient-led. LUNGeivity doesn't assume what the patient community needs; they want to hear from patients and their loved ones. The EGFR Resisters previously partnered with LUNGeivity on Project PRIORITY, the largest IRB-approved real-world longitudinal study of diagnosis, treatment, side effects, and psychosocial issues in the EGFR-positive lung cancer community. LUNGeivity was our partner, but because the research was patient-led and patient-funded, we were part of every discussion and every decision — the experience was so empowering and rewarding! Due to LUNGeivity's invaluable support and

collaboration on this project, we have been able to identify unmet patient needs in the community that have led to our decision to issue our Request for Proposals (RFP) for EGFR-positive lung cancer research.

There are almost no words to describe what this means as a lung cancer patient. In contrast to being a participant in research, such as through a clinical trial, we as patients are actually part of the team that is directly working to accelerate research. The EGFR Resisters group works as a full and equal partner with LUNGeivity through every step of the RFP process, starting with funding and ending with project selection. The ultimate decision of which project to choose rests with the EGFR Resisters as the funders and drivers of the award. Our partnership is the epitome of patient-centered research, illustrating the recent paradigm shift to include patients as true partners in research

The EGFR Resisters is a patient and caregiver group, not a 501(c)3, so the fact that the EGFR Resisters has been able to raise over \$200,000 on its own to accelerate research is incredibly exciting! This is only possible because people are living longer with lung cancer due to improved treatments that lengthen our survival. Think about it...an entire research project on EGFR-positive lung cancer is only possible because of us. Ten years ago, we would never have been able to work together in this way as a community: there were too few survivors and no way to connect easily. It is inspiring and promising that the EGFR Resisters can now spearhead a research project for which we/patients choose the areas of focus that address the unmet needs in our community. We are so grateful for our powerful and motivated online patient and caregiver community that understands how important and necessary research is to improve outcomes in patients.

Most of us are on treatments that have only been approved in the past 10 years, and while they have allowed us to live longer and better lives, too many of us are still depending on the next promising treatment. We are confident that the EGFR Resisters and LUNGeivity share the same goal: to make EGFR-positive lung cancer into a manageable, chronic disease. What if the research we fund translates to an intervention or discovery that leads to more and better options for our community, or, ultimately, a cure? THAT is exciting. THAT is the hope that our community needs and deserves!

Another Great Year for Lung Cancer Research



Upal Basu Roy

2020 has so far been a banner year for progress in the treatment of lung cancer. The successes of this year build on scientific advances from the past decade in which personalized lung cancer treatments have revolutionized the way we think about cancer and the way we treat patients.

According to a study published in the *New England Journal of Medicine* in August 2020, scientists saw mortality decline in patients diagnosed with non-small cell lung cancer (NSCLC) and (to a lesser degree) small cell lung cancer (SCLC) during 2006-2013. This decline in mortality up until 2013 was likely due to a decline in new cases (incidence) of lung cancer. However, the decline in mortality for NSCLC patients became even more pronounced starting in 2013, shortly after targeted therapies for EGFR and ALK were approved for NSCLC patients by the U.S. Food and Drug Administration (FDA) and were included in treatment guidelines as the standard of care. These results continued through the end of the study period in 2016, and they highlight the importance of ongoing research to develop new treatment options for lung cancer.

“There has been continued progress in the treatment of lung cancer over the past decade,” says Charles Rudin, MD, PhD, professor and chief of Thoracic Oncology Service at Memorial Sloan Kettering Cancer Center and chairman of LUNGevery’s Scientific Advisory Board. “We are improving upon our previous techniques and expanding our knowledge base to improve survival and quality of life for patients.”

“Tumor cells can have key genomic mutations that are critical for the development of cancer,” says Dr. Upal Basu Roy, executive director, LUNGevery Research. “A number of driver mutations, including EGFR, ALK, ROS1, NTRK, MET, BRAF V600E, and RET, already have approved treatments designed to specifically impede the molecular pathways responsible for cancer development.”

Lung cancer treatment options are exploding with hope and possibility for all lung cancer patients and their families. Approving the use of high-quality treatment options and maintaining updated treatment guidelines has a significant impact on outcomes for lung cancer patients and their families.

“The great progress that we have seen in the treatment of lung cancer underscores the importance of supporting lung cancer research,” says Dr. Basu Roy. “We are fortunate to be building on this momentum to bring us closer to a world we all dream of... a world where no one dies of lung cancer.”

NEW FDA APPROVED TREATMENTS IN 2020

So far in 2020, the FDA has approved several targeted treatment options for advanced-stage non-small cell lung cancer (NSCLC), including:

- **capmatinib (Tabrecta®)**: for the treatment of NSCLC with the MET exon 14 skipping mutation
- **brigatinib (Alunbrig®)**: for the first-line treatment of ALK-positive NSCLC
- **ramucirumab (Cyramza®) (an angiogenesis inhibitor) in combination with the targeted therapy erlotinib (Tarceva®)**: for the first-line treatment of NSCLC with EGFR exon 19 deletions or exon 21 (L858R) substitution mutations
- **pralsetinib (Gareto™)**: for the treatment of RET fusion-positive NSCLC
- **selpercatinib (Retevmo™)**: for the treatment of RET fusion-positive NSCLC

“There are many other promising research studies and clinical trials underway to improve outcomes for lung cancer patients with driver mutations,” says Dr. Basu Roy. “Many treatments are still being optimized, vetted for safety and efficacy, or tested in large-scale trials to prove their worth.”

Another major class of treatments for lung cancer is immunotherapy, which leverages the patient’s natural immune system to combat cancer. As with targeted therapies, the FDA in 2020 has approved several new immunotherapy treatments for NSCLC patients, including:

- **atezolizumab (Tecentriq®)**: for the first-line treatment of NSCLC with high levels of the PD-L1 protein and without an EGFR or ALK genomic mutation
- **nivolumab (Opdivo®)**: in combination with ipilimumab (Yervoy®) and two cycles of platinum-doublet chemotherapy, for the treatment of metastatic or recurrent NSCLC with no EGFR or ALK genomic mutations
- **nivolumab (Opdivo®)**: in combination with ipilimumab (Yervoy®) for the first-line treatment of metastatic NSCLC expressing PD-L1 (greater than or equal to 1%) with no EGFR or ALK genomic mutations

In addition, **pembrolizumab (Keytruda®)** has now been approved for the treatment of solid tumors that cannot be treated with surgery or are metastatic, are tumor mutational burden-high, and have progressed following prior treatment and for which there are no satisfactory alternative treatment options. (Tumor mutational burden [TMB] is the total number of mutations found in the DNA of cancer cells.)

The FDA this year has also improved two new treatment options for small cell patients: **durvalumab (Imfinzi®)**, an immunotherapy drug, in combination with etoposide and either carboplatin or cisplatin as a first-line treatment, and **lurbinectedin (Zepzelca™)**, a chemotherapy drug for use when small cell lung cancer recurs after initial treatment.

2020 CAREER DEVELOPMENT AWARDS GO TO THREE YOUNG INVESTIGATORS

LUNgevity Foundation is proud to present three outstanding, young researchers with a 2020 Career Development Award (CDA): Drs. Kathryn Arbour, Carl Gay, and Sean Pitroda. These substantial financial awards serve two purposes: they fund critical lung cancer research projects while offering the recipients financial support and scientific guidance early in their 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 29 researchers.

The 2020 awardees are focused on three important questions:

- How can we prevent resistance to a drug that targets the KRAS G12C mutation among non-small cell lung cancer patients?
- How can we determine which small lung cancer patients will respond to immunotherapy and targeted therapy?
- How can we determine which non-small cell lung cancer patients will respond to an immunotherapy-radiation therapy combination treatment?



KATHRYN ARBOUR, MD
Memorial Sloan Kettering Cancer Center

Mechanisms of resistance to direct KRAS G12C inhibition

Mutations in the KRAS gene have been identified in 25%-30% of cases of lung adenocarcinoma, a type of non-small cell lung cancer. While molecularly

targeted therapies have proven effective for other driver oncogenes, such as EGFR and ALK, the clinical activity of molecularly targeted therapy in KRAS-mutant lung cancer has been limited as KRAS was long considered an “undruggable” target. KRAS G12C mutations are the most common subtype in lung adenocarcinoma and are present in 12% of lung cancer patients overall. Drugs that specifically block the KRAS G12C mutation have been in clinical trials since 2018. However, as with other targeted therapies, it is anticipated that cancer cells will eventually develop resistance to these new drugs. Dr. Kathryn Arbour’s laboratory is studying pathways that confer resistance to KRAS G12C-blocking drugs. Her research has shown that lung cancer cells can escape the effects of these new drugs by turning on another protein, the SHP2 protein. Dr. Arbour hypothesizes that a combination therapy approach that blocks the effects of both the KRAS G12C mutation and the SHP2 protein will prolong the effect of the KRAS-blocking drug. Through the LUNgevity Career Development Award, she will be testing a combination treatment regimen (MRTX849 for KRAS G12C and TNO155 for SHP2) in specialized mouse models of KRAS-mutant lung cancer. She will further analyze blood samples from patients who are currently receiving the MRTX849 drug and proactively monitor how these patients are developing resistance to MRTX849, so that new drugs, such as TNO155, can be added to their treatment regimen.



CARL GAY, MD, PHD

The University of Texas MD Anderson Cancer Center

SCLC molecular subtypes to predict targeted and immune therapy response

Small cell lung cancer (SCLC) comprises 15% of all diagnosed cases of lung cancer. It usually responds to initial chemotherapy; however, it inevitably becomes resistant to the chemotherapy and progresses. New therapeutics strategies to treat this highly aggressive tumor is a huge unmet need. In 2019, immunotherapy-chemotherapy combinations were approved for the first-line treatment of SCLC. These treatments are somewhat more effective than traditional chemotherapy. Also, they are given to every patient (no patient selection). Dr. Gay’s laboratory has shown in mouse models of the disease that immunotherapy can be more effective in SCLC when it is combined with a new class of drugs called DDR inhibitors (DNA Damage Repair Inhibitors). In parallel, they have developed a biomarker signature that can identify patients who are likely to benefit from DDR inhibitors. In the proposed project, Dr. Gay and his team will test the immunotherapy-DDR inhibitor combination in patients and validate their biomarker profile, with the ultimate goals of developing a new drug therapy combination and determining which patients are likely to benefit from it.



SEAN PITRODA, MD
The University of Chicago

Predictive biomarkers of radio-immunotherapeutic response in NSCLC

Currently, five immune checkpoint inhibitors are approved by the FDA for the treatment of a subset of advanced-stage NSCLC. Recently, an immunotherapy-immunotherapy combination regimen and an immunotherapy-immunotherapy-chemotherapy combination have been shown to be effective in both advanced-stage squamous and non-squamous NSCLC patients. Despite this promise, immunotherapy works only in a subset of patients — around 20%-25% of patients who receive immunotherapy will show a durable response. In an effort to augment the effect of immunotherapy, doctors often combine radiation therapy with immunotherapy. The radiation therapy leads to the death of cancer cells, thereby releasing cancer-related proteins and making the cancer more visible to the immune system. Use of immunotherapy in combination with radiation therapy augments the effects of immunotherapy alone. Using well-established genomic and molecular biology tools, Dr. Pitroda and his team will develop a biomarker signature that can predict which patients are the most likely to benefit from the immunotherapy-radiation therapy combination. This is a hugely important question to answer because it will help doctors decide which patients can be spared the combination treatment if they are unlikely to respond to it.

Research Awards Funded by ALK Positive Patient Group in Second Collaboration with LUNGeVity Foundation

ALK Positive, a group of 2,000+ ALK-positive lung cancer patients and their caregivers in 50+ countries, works to ensure a good future for all patients affected by ALK-positive non-small cell lung cancer.

Partnering with LUNGeVity, the ALK Positive members raise significant research dollars and then select the high-impact research that will most quickly improve outcomes for the approximately 5% of non-small cell lung cancer patients who are ALK-positive.

In September 2020, ALK Positive and LUNGeVity Foundation granted their second set of awards with funds raised by ALK Positive. These three two-year awards total \$1,600,000.



Phase 1 first-in human clinical trial with a therapeutic ALK vaccine in patients with ALK+ NSCLC

Mark Awad, MD, PhD
Dana-Farber Cancer Institute



Overcoming bypass signaling to enhance clinical responses in ALK-positive lung cancer

Ibiayi Dagogo-Jack, MD
Massachusetts General Hospital



Overcoming ALK resistance with covalent cysteine-reactive inhibitors

A. John Iafrate, MD, PhD
Massachusetts General Hospital

Dr. Mark Awad's project, a clinical trial, will test a therapeutic vaccine. This builds on his 2018 grant aimed at understanding the antibody response against the ALK protein and to determine which parts of the ALK protein trigger an immune response. If successful, this would be the first vaccine for ALK-positive patients.

Dr. Ibiayi Dagogo-Jack's clinical trial will determine how to improve clinical response in ALK-positive patients by using combination therapies to combat acquired resistance to ALK tyrosine kinase inhibitors. Dr. A John Iafrate's project will determine a way to overcome resistance to ALK medications using a novel approach that targets the ALK protein for degradation.

These projects combine the patient voice with the scientific rigor demanded of such critical research, and we are hopeful that they will lead to saved lives.

The Rolke Family Honors Kristie Rolke Smith's Memory

BY PARTNERING WITH LUNGEVITY FOUNDATION



Kristie Rolke Smith

The Rolke family established the Kristie Rolke Smith Career Development Award in partnership with LUNGeVity to create a legacy of hope and impact the future of lung cancer research.

The Rolke family reached out to LUNGeVity to make a transformational gift in Kristie's memory based on LUNGeVity's reputation as the preeminent private funder of lung cancer research. The family chose to fund **Dr. Kathryn Arbour** of Memorial Sloan Kettering in New York because her

research project, *Mechanisms of resistance to direct KRAS G12C inhibition*, focuses on drugs to target the KRAS mutation — a common mutation found in lung cancer patients that has long been considered undruggable. Dr. Arbour is honored to receive this award in memory of such a remarkable young woman. Kristie was devoted to her husband, children, and family. The Rolke family shared that to know Kristie meant that you walked away with a smile every time you saw her or spoke to her. Dr. Arbour and LUNGeVity Foundation are grateful for the opportunity to remember Kristie in such an extraordinary way while advancing lung cancer research.

A Visit with Tom Galli



Tom Galli

LUNGevity Foundation board member and lung cancer survivor discusses how both the organization and the Lung Cancer Support Community forum (LCSC) have become lifelines in the age of COVID-19 and beyond.

When did you initially find LUNGevity?

I joined LUNGevity in May 2015, after the demise of an online support community called RedToenail.org, a general cancer forum started by a radiologist in San Diego who got diagnosed with lung cancer and who was never a smoker.

The doctor vowed to paint a toenail red every year that he survived the disease. And he painted five toenails red before he passed away. I'm about to paint 16 toes in February. So, I have to figure out how to get 16 toes.

What was your experience looking for support?

For the first couple of years, I didn't have a support group. That's why LUNGevity is important to me.

I'm a retired soldier, and we don't like to admit that we have depression. It's very unsoldierly to admit that something is getting us down when we're always supposed to be energized about charging into the enemy. So, it was very hard in the first couple of years of treatment to realize that I was depressed.

And I was.

I've had a lot of lung cancer recurrences. Even nearing 16 years of survival, my oncologist will not use the word "cure" with me. So, I'm not out of the woods. But when I had that bout of depression, I talked about it with my general practitioner. He got me involved in professional counseling and suggested that I go out and find an in-person support group.

When you're in treatment, just getting yourself up and going to an in-person support group becomes tough. You've got all these side effects, you feel lousy, and your life is reduced to a repetitive schedule. Well, the online Lung Cancer Support Community is my lung cancer support group. It's where I go to address my anxiety with people who understand. Nobody on that forum is going to chide me for whether I smoked or not. All they care about is that I have the disease.

What do you want people to know about the Lung Cancer Support Community?

It's a very important resource for folks for four reasons. First, it's the only place where a person can go to learn how it feels to have lung cancer — including the diagnosis and treatment. We've got doctors and practitioners who know how to diagnose and treat it. But, not a single one of them knows what it feels like to live with it. You come to the forum to learn.

Second, we are a community on the forum; we answer questions based on our individual experiences as patients and caregivers about side effects, possible treatments, and a full range of things. We're not physicians, and we do not give medical advice. But every one of us has a Ph.D. in living with the side effects and enduring treatments for lung cancer. This is the place where you can go to learn about other treatments that you might want to speak with your doctor about. Plus, on the LUNGevity website there is a section called Lung Cancer 101, where we can link in our answers and specific

aspects about the disease that have been vetted by LUNGevity's Scientific Advisory Board and other experts. It becomes a very powerful thing.

Third, LCSC is a 24/7 resource. Many of us don't sleep a lot because of side effects. Even at two o'clock in the morning, I've seen people ask questions, and they get answered. And we have an international footprint. So, there are people in Singapore who are awake when we're sleeping. There are people in Great Britain who are ending their day when we're beginning ours. A question comes up on the forum, and somebody picks it up almost right away. There are blogs that archive information that anyone can access as well.

Finally, the most important thing about the Lung Cancer Support Community forum is that we serve as evidence of survival. When I first got diagnosed, there were not a lot of options for treatment. But now, when you consider the future after that initial diagnosis, and you see me still sitting here banging out information and answers on the forum after nearly 16 years, you conclude that hey, people make it.

There are other people on the forum who've got eight years, 10 years, 12 years. We've got small cell survivors who have lived six years. So, just the fact that we are there and that we are alive is a real message for the newly diagnosed.

Why is the Lung Cancer Support Community important during the COVID-19 pandemic?

The best strategy for lung cancer patients is to never get COVID-19 or influenza. For me, this means staying indoors, which I've done since February.

There are a lot of us out there who are just COVID-cooped up like me. And so the Lung Cancer Support Community and the weekly Zoom meet-ups have become my only tie to the outside world. This is important since this isolation has been hard because the disease itself is isolating.

Join the Lung Cancer Support Community at: [LUNGevity.org/lcsc](https://www.LUNGevity.org/lcsc)

LUNgevity Goes Virtual

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The conference took place on an immersive virtual platform with many online meet-up opportunities for conference goers, including two fireside chats hosted by long-term lung cancer survivors, as well as 11 networking lounge sessions divided into mutation-specific and other lung cancer groups.

The virtual ILCSC created a unique opportunity to build a new global

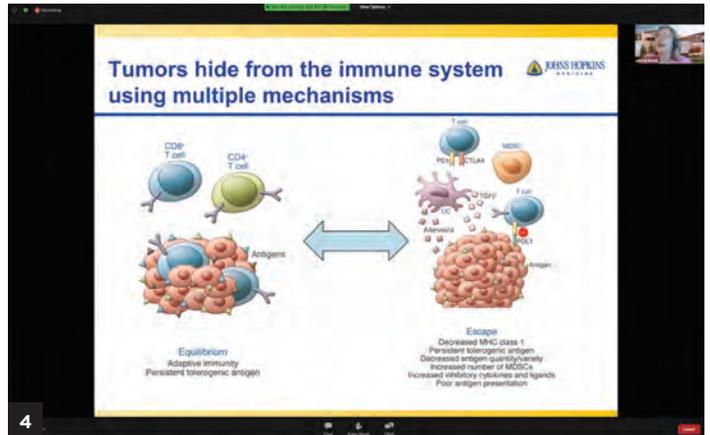
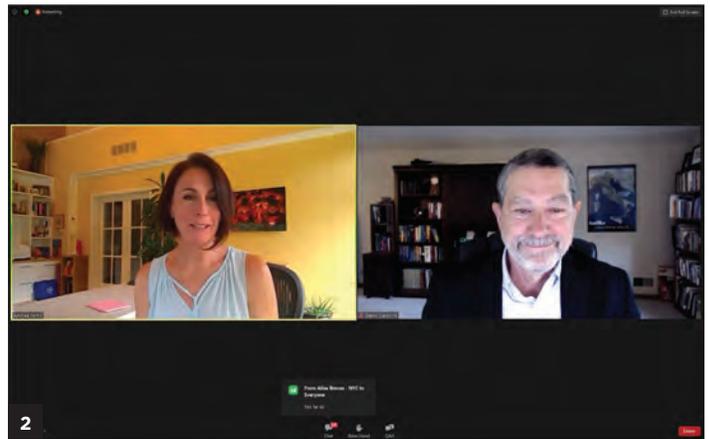
community of lung cancer survivors and their care teams, many of whom could not have attended an in-person conference due to health issues or travel restrictions.

Missed a session? Many sessions are available by visiting <https://LUNgevity.org/ilcsc> to watch them at your leisure or share with your family and friends.

Want to keep the learning going? Join our Friday Zoom meetings, opportunities to get to know other lung cancer survivors

and caregivers and discuss issues important to you. We also encourage you to connect with one of our many Facebook groups or join the conversation at the online Lung Cancer Support Community.

Because of the overwhelmingly positive response, LUNgevity will host a second ILCSC virtually in August 2021, while the traditional HOPE/COPE Summit will be held in person May 14th through the 16th.



(1) Debbie Holt leads conference-goers in a virtual Yoga 4 Cancer workout. **(2)** Andrea Ferris, president and CEO of LUNgevity, and LUNgevity Scientific Advisory Board member David P. Carbone, MD, Ph.D., welcome conference attendees. **(3)** Jeanne Regnante, LUNgevity Foundation chief health equity and diversity officer (top right) moderates a breakout session featuring Karriem Watson, DHS, MS, MPH; and LUNgevity board members Robert Winn, MD; and Nichelle Stigger. **(4)** Julie Brahmmer, MD, explains the basics of immunotherapy.

The Action Network

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The Action Network will help increase awareness about lung cancer while amplifying LUNgevity's ongoing policy work. This past February, LUNgevity released the Lung Cancer Scorecard. This state-by-state study compared access to



screening, comprehensive biomarker testing, and clinical trials to uncover disparities in lung cancer patient care based on location. It also offered viable solutions to achieve healthcare equity. This report laid out specific areas that need to be addressed to improve care in each state. With the Network, advocates can easily help us address the pain points identified in this report, along with other important

issues, resulting in our efforts making a deeper impact.

“LUNgevity has long been advocating for issues important to those living with lung cancer,” says Kristen Santiago, senior director of Public Policy of LUNgevity Foundation. “This new platform will help us unite and activate our already engaged community to make a tangible, impactful difference on these issues.”

Those interested can register now at: action.LUNgevity.org. They can also sign up to receive emails and alerts from LUNgevity when issues of interest or new legislation or policies need support.

National Celebration of Hope *Had a New twist*

LUNgevity Foundation held its National Celebration of Hope on October 21, 2020, raising \$550,000. The virtual event, hosted by WNBC weather anchor Dave Price and featuring a performance by the Young People's Chorus of New York City, brought together business leaders, philanthropists, policymakers, and advocates to celebrate and support the progress of lung cancer research.

The funds raised at this year's event are more important than ever as the coronavirus pandemic has put critical, life-altering lung cancer research at risk by disrupting momentum and impacting progress for those affected by the disease.

As part of the evening's festivities, LUNgevity honored the following individuals and organizations who have made notable contributions to the lung cancer community.

FACE OF HOPE AWARD RECIPIENTS

Jill Feldman

Lung Cancer Survivor and Advocate

Frederick P. Smith, MD, FACP

Attending Medical Oncologist,

Sibley Memorial Hospital

Clinical Associate Professor,

Georgetown University

School of Medicine

Clinical Assistant Professor,

Johns Hopkins School of Medicine

CHAMPION OF HOPE AWARD FOR VOLUNTEER LEADERSHIP

Kathy Cuddy

Lung cancer advocate and

LUNgevity volunteer

FACE OF HOPE AWARD FOR CORPORATE LEADERSHIP

AstraZeneca

LUNgevity would like to thank its National Celebration of Hope co-chairs, who helped to transition our spring and fall galas into a moving virtual experience:

Brent Barnhart

Vice President

UBS Private Management

Nancy Cohen

Lung Cancer Patient and Advocate

Andre Owens

Partner

WilmerHale

Natalie Cohen Smith

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LUNgevity extends its appreciation to our 2020 National Celebration of Hope Sponsors and Donors

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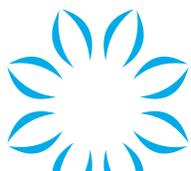
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LUNgevity also extends its appreciation to those donors whose gifts arrived after the deadline, as well as to those who supported the Celebration of Hope with gifts in other amounts or who wish to remain anonymous.





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LUNGevity Kept the Fundraising Pace with Two Virtual Run and Walks in October

In response to the ongoing COVID-19 public health crisis, LUNGevity Foundation elected to move two of its signature fall run/walk events online.



From October 1st through the 17th TEAM LUNGevity held its first e-Race Lung Cancer event.

The virtual event offered participants the chance to raise funds while running the race of their choice (5K, 10K, half-marathon, marathon, or marathon relay (cumulative 26.2 miles). At the time of publication, the event has generated over \$62,000 from 235 runners — including 15 lung cancer survivors.

On Saturday, October 24, the organization hosted its fall Breathe Deep Together — a virtual walk/run designed to unite supporters for a morning of celebration, hope, and remembrance for all those affected by lung cancer. The event kicked off with a special Facebook Live that was hosted by NBC Washington’s chief meteorologist, Doug Kammerer, and featuring a keynote address from former LUNGevity Career Development Awardee Kathryn O’Donnell, PhD, before the 144 teams set off to walk. To date, the race has raised over \$400,000 from 632 walkers and runners.



Support LUNGevity With a Year-End Gift

LUNGevity counts on your support to fund research, education, and resources to the lung cancer community. Please remember LUNGevity in your year-end giving plans by making a gift.

You may give a cash gift, gift of stock, or IRA Qualified Charitable distribution.

Donate online at www.lungevity.org or use this PayPal QRcode to make your donation today.



WEBSITE: www.LUNGevity.org

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