Bringing the Patient Voice to Healthcare

**Introducing Patient FoRCe, the LUNGevity Patient-Focused Research Center**

LUNGevity Foundation has launched Patient FoRCe, the first-ever critical bridge to connect the voices of lung cancer patients with healthcare professionals, regulators, policymakers, and developers of drugs.

LUNGevity is leading the way in changing the paradigm of cancer treatment—from assuming patient wishes to evidence-based conclusions about what patients value. Through Patient FoRCe, lung cancer patient voices will be heard and heeded as policy is developed, research is conducted, and treatment decisions are made.

Patient FoRCe will undertake pioneering studies of those living with lung cancer, collecting and sharing robust qualitative and quantitative data about lung cancer patients’ preferences and experiences to inform treatment, as well as relevant policy and research protocols.

Patient FoRCe’s immediate focus will include continuing a study of patient preferences and experiences regarding access to care, treatment and diagnostic options, and the impact of symptoms on continued on page 3.

“Our goal is to uncover gaps in information, misperceptions about patient attitudes, and areas of unmet patient needs. LUNGevity is the only organization driving this type of change for the lung cancer community.”

**UPAL BASU ROY, PHD, MPH**
LUNGevity, Director of Patient FoRCe and Director of Research and Policy

Call the Lung Cancer HELPLine

LUNGevity understands the emotional, financial, and support challenges of a lung cancer diagnosis, and is now offering, in partnership with CancerCare®, the Lung Cancer HELPLine, a free, personalized support service for patients and caregivers at any point along a lung cancer journey. Oncology social workers are available to help patients, caregivers, and families manage these challenges.

Charitable funding for the HELPLine was generously provided by Bristol-Myers Squibb and Genentech.

For assistance, call the toll-free HELPLine at 844-360-LUNG (5864), 9:00 a.m.-5:00 p.m. Eastern Time, Monday through Friday, to receive:

- Information about lung cancer and treatment options
- Personalized support and counseling
- Referrals to financial assistance resources for needs including pain medication, homecare, childcare, medical supplies, transportation for treatment, and copayment assistance

UPDATES ON PROGRESS IN OUR DRIVE TO END LUNG CANCER
May Is HOPE Month

When LUNGevity designated May as Lung Cancer Hope Month six years ago, the options for lung cancer patients were few. Much has changed since then. Today, we celebrate the incredible progress being made in lung cancer research, survivorship, and quality of life.

The embodiment of that celebration is our annual National HOPE Summit, an educational, community-building conference for lung cancer patients, survivors, and caregivers. This year’s event in April was the largest gathering of lung cancer survivors to date! Highlights included a keynote speech and performance by country star and cancer advocate Wade Hayes, and speakers from the Department of Defense and NIH, as well as updates from the country’s leading oncologists.

Many of you are already joining our movement to raise awareness and funds for research and support, and we thank you! If you want to get involved, LUNGevity provides a host of ways to do so, from attending a health fair in your community and distributing LUNGevity materials to writing a blog telling of your personal lung cancer experience. You can also join our Breathe Deep walks, create your own event, or fundraise as a member of Team LUNGevity for endurance events.

Go to www.LUNGevity.org to learn more. Together, we can make the lung cancer community stronger and reach more people when they need support.

Join the movement!

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LUNGevity Foundation is a 501(c)(3) nonprofit organization.
LUNGevity Welcomes Two New Experts to Scientific Advisory Board

LUNGevity's Scientific Advisory Board members guide LUNGevity's scientific strategy and research program. Its members include leaders in fields critical to the early detection and treatment of lung cancer, including proteomics, pulmonology, biostatistics, radiology, immunotherapy, and others. The Foundation is proud to announce the newest members of the Scientific Advisory Board, Edward B. Garon, MD, and Alice T. Shaw, MD, PhD. Both Dr. Garon and Dr. Shaw have made significant contributions to the development of drugs for the treatment of non-small cell lung cancer (NSCLC).

Dr. Garon is the Director of the Thoracic Oncology Program at the Jonsson Comprehensive Cancer Center at UCLA and Associate Professor of Medicine in the Division of Hematology-Oncology at David Geffen School of Medicine at UCLA. He has been the principal investigator of peer-reviewed grants from various funding organizations, including the National Cancer Institute. His focus is on clinical research and biomarker development. He has served as the principal investigator on national and international phase I, II, and III clinical trials. Among these are trials that have led to the approval of drugs for the treatment of NSCLC, including ramucirumab (Cyramza®) and the immunotherapy pembrolizumab (Keytruda®).

Dr. Shaw is the Director of the Center for Thoracic Cancers and the Paula O’Keeffe Endowed Chair of Thoracic Oncology at Massachusetts General Hospital. She is also an Associate Professor of Medicine at Harvard Medical School. In addition to caring for patients with lung cancer, Dr. Shaw also performs clinical and translational research. Her clinical research focuses on subsets of NSCLC that have unique driver mutations, such as EGFR, ALK, and ROS1. Her translational research focuses on understanding and making clear the mechanisms of resistance to targeted therapies; she is currently developing novel combination treatment strategies. Dr. Shaw’s research has helped to develop numerous FDA-approved targeted therapies for patients with oncogene-driven NSCLC, such as crizotinib (Xalkori®) for patients with ALK rearrangements and ROS1 fusions.

Bringing the Patient Voice to Healthcare

continued from page 1

daily living, as well as conducting studies to facilitate patients’ access to biomarker testing, which is essential to implementing precision medicine. Patient FoRCe will also initiate a study into increasing adherence to lung cancer screening protocols for people at high risk and begin phase 2 of our studies on attitudes toward rebiopsies and reaching unreached patients.

LUNGevity formally announced Patient FoRCe at the American Association for Cancer Research’s 2017 Annual Meeting in Washington, DC, on Sunday, April 2. Andrea Ferris spoke to the urgency of the initiative, saying, “For too long, public policy, the practice of medicine, and drug development have not adequately integrated the viewpoint of patients. LUNGevity is determined to change that paradigm. By incorporating the patient’s voice into every step of the process—in policymaking, in trials, in treatments—we will improve outcomes for those diagnosed with lung cancer.”

“Our goal is to uncover gaps in information, misperceptions about patient attitudes, and areas of unmet patient need,” explained Dr. Upal Basu Roy, Director of Patient FoRCe. “LUNGevity is the only organization driving this type of change for the lung cancer community, and we anticipate that our findings will shape the future of lung cancer care.”

For more information about Patient FoRCe, visit www.LUNGevity.org/patientforce.
The annual LUNGevity Celebration of HOPE gala in New York City attracts national leaders in business, philanthropy, and science. 2016’s glittering event took place at the Mandarin Oriental, where Dow Chemical Company Chairman and CEO Andrew Liveris was honored for his ongoing support of those living with lung cancer, and Joel Beetsch, VP Patient Advocacy, accepted the HOPE Award for Corporate Leadership on behalf of Celgene. 11-year cancer survivor, blogger, and artist Linnea Olson received the Face of HOPE award for her dedicated advocacy for the lung cancer community.

1) Dinner Chairs Rosemary and James Marquardt. 2) LUNGevity research grant awardees Piro Lito, MD, PhD, and John Poirier, PhD, and LUNGevity Scientific Advisory Board member Paul Paik, MD. 3) Ashley Bernhard, consultant, and Jason Bernhard, Lazard, with designer Sulaika Zarruck Gormley and Richard Gormley, Guggenheim Securities. 4) Favorite WNBC-TV journalist and weatherman Dave Price, the evening’s surprise emcee, with Sung Poblete, CEO of Stand Up To Cancer. 5) The Dow Chemical Company Chairman and CEO Andrew Liveris. 6) Honorary Chair Lynn Doughtie, Chairman and CEO of KPMG, welcomes guests to the Gala. 7) Lung cancer survivor Lois Robb and LUNGevity Scientific Advisory Board Chair Dr. Charles Rudin. 8) Celgene VP Patient Advocacy Joel Beetsch and LUNGevity President and CEO Andrea Ferris. 9) Lung cancer survivor Amanda Kouri, surrounded by her supporters, raised money for LUNGevity HOPE Summit scholarships. 10) Cancer survivor Linnea Olson. 11) The Dow Chemical Company Executive Vice President and General Counsel Charles Kalil and Mona Kalil, Ann Stern and LUNGevity Board member Paul Stern, and Paula Liveris and Dow Chairman and CEO Andrew Liveris. 12) The Celgene team celebrates Celgene’s receipt of the HOPE Award for Corporate Leadership.
More Lung Cancer Treatments Are on Their Way

An update from Upal Basu Roy, PhD, MPH, LUNGevity, Director of PatientFoRCe and Director of Research and Policy

Based on what I learned at the 17th Annual Targeted Therapies of the Treatment of Lung Cancer conference in February in Santa Monica, California, 2017 is going to be an important year for progress in targeted therapies. The conference brings together doctors and scientists from all over the globe to discuss the advances that will result in the best care for lung cancer patients.

While other cancer conferences such as ASCO and World Lung are spread over four days, this conference is unique in that there are more than 200 short presentations packed into just two-and-a-half days! Coffee was my best friend for those two-and-a-half days while I learned how the field is evolving. I took away three big themes from these meetings.

**Doctors are learning more about the WHY and the WHEN for combination therapies.**

An important theme that resonated with me was the idea of “rational” combination therapies. We have made a lot of progress in understanding how to combine different treatments—which ones to combine and in what sequence—so that the combination is very effective with minimal side effects.

For example, a combination that is being tested in clinical trials is immunotherapy with chemotherapy. Cancers cells escape from the immune system by wearing an invisibility cloak. Current immunotherapy drugs (called checkpoint inhibitors) work by uncloaking cancer cells. Combining chemotherapy with immunotherapy seems to make this uncloaking process extremely efficient. When patients receive the immuno-chemo combination, they respond faster than with immunotherapy alone. Also, preliminary results from clinical trials suggest that the sequence of giving the two treatments matters. There may be more benefit when immunotherapy is given after initial chemotherapy. However, it is still too early to tell. We are waiting for the final readout of these clinical trials.

**We are learning about existing targetable mutations and adding new mutations to our list: the pie has more slices!**

I still remember the year 2004, when I was a graduate student in cancer biology. It was the year that the first mutation in non-small cell lung cancer (NSCLC)—in the EGFR gene—was discovered. Soon, pie charts that showed that around 10%-35% of NSCLC patients have a mutation in the EGFR gene surfaced in textbooks. This discovery led to the development of tyrosine kinase inhibitors (TKIs), which block the growth-promoting effects of EGFR mutations. We have come a long way since then. Now at least 10 driver mutations (mutations that promote the growth of cancer cells) in lung adenocarcinoma (a type of NSCLC) have been identified (alterations in the EGFR, ALK, ROS1, RET, ERB2/HER2, MET, TRK, BRAF, and KRAS genes). TKIs that block the effect of some of these driver mutations already exist or are in clinical development. However, lung cancer cells are shrewd—despite an initial response to TKIs, they learn to outwit the effects of these drugs. So scientists are hard at work! They are developing TKIs that block the effects of these mutations, and are staying a step ahead, studying how cancer cells become resistant to the effects of TKIs. Their ultimate goal is to make sure that doctors have more than one tool in their toolkit, so that drug B is ready when cancer cells become resistant to drug A. This has been made possible because of the remarkable progress we have made in understanding the biology of lung cancer.

The best example of progress in this area has occurred in the EGFR space. Patients whose lung cancers test positive for an EGFR mutation are
treated with 1st- or 2nd-generation TKIs. When their cancer becomes resistant to these TKIs due to another mutation in the EGFR gene (often the T790M mutation), doctors prescribe a 3rd-generation TKI such as osimertinib. Now clinical trials with osimertinib in the first-line setting are showing promise, and the drug may soon be approved for first-line treatment. Scientists are working on the next piece of the puzzle—learning how cancer cells outwit osimertinib.

Progress in the field of ALK TKIs has also been rapid. Now, patients who have progressed on 1st-generation ALK TKIs are prescribed 2nd-generation drugs. Scientists are working on 3rd-generation ALK TKIs (such as lorlatinib) that would provide options to patients whose cancers have developed resistance to 2nd-generation drugs. Drug development for ROS1 is fast catching up. In 2016, the FDA approved crizotinib in the first-line setting for ROS1-positive lung cancers. New ROS1 TKIs are already in clinical development.

Other promising areas of clinical development are with TKIs that target mutations in the MET gene and in the BRAF gene. I am really excited to see these drugs move closer to the clinic.

**We are making progress in treatment options for other lung cancer subtypes, such as small cell (SCLC) and squamous cell lung cancer.**

Currently, targeted agents are available for a subset of adenocarcinoma patients, whose tumors test positive for an actionable mutation. With the rapid progress we have made in understanding the biology of lung cancer, treatment options for other subtypes such as squamous cell lung cancer and SCLC are now being tested in clinical trials.

Chemotherapy was the mainstay of treatment for squamous cell lung cancer. However, that has changed with the approval of immunotherapy in the first-line setting for a subset of squamous patients. Also, targeted agents for squamous patients are being tested in biomarker-driven clinical trials such as Lung-MAP.

We are also seeing incredible progress in the area of small cell lung cancer (SCLC). RovaT—a drug that targets a protein called Delta-like 3 (DLL3)—is continuing to show promise in clinical trials. In some SCLC patients, large quantities of DLL3 are produced. RovaT seeks out SCLC cells that make DLL3 and delivers an effective toxic drug to those cells. It may be the first biomarker-driven treatment showing promise in small cell. Another promising class of drugs is PARP inhibitors. These drugs work by making SCLC cells unable to repair themselves after they have been treated with chemotherapy. I am eager to see the final readout of the chemotherapy-PARP inhibitor combination trials.

I am sure you are surprised that I didn’t mention immunotherapy as a separate theme. In fact, the field of immunotherapy is exploding—with research on how to select patients who may benefit, how best to combine immunotherapy with other treatment options, and use of immunotherapy in early-stage lung cancer. LUNGevity SAB member Dr. Julie Brahmer beautifully summed up the progress so far in immunotherapy in her keynote presentation at the conference: “With immunotherapy, we have already gone to the moon. Now, let’s go to Mars!”
LUNGevity awardee Dr. Julien Sage of Stanford University and LUNGevity science writer Juhi Kunde recently discussed how a simple conversation at a networking event about small cell lung cancer (SCLC) paved the way for innovative research that has the potential to improve survival rates for patients.

Currently, there is a lot of research being conducted to try to use the body’s natural defenses—the immune system—to eradicate disease. This field, called immunotherapy, is growing quickly and providing promising results in many types of cancer. Unfortunately, SCLC continues to have low survival rates. Dr. Sage and his team of collaborators received a 2014 LUNGevity Targeted Therapeutics Award to develop immunotherapy techniques that target small cell. Dr. Sage spoke about this cutting-edge research and the LUNGevity funding that made his work possible.

How did you get the idea for this project?

I have been interested in small cell for about 15 years. My post-doctoral research involved SCLC, and I have continued to study the disease in my own lab at Stanford University. A couple of years ago, I attended a networking retreat for MD/PhD students and their mentors, where I had the opportunity to brainstorm and discuss new research ideas with scientists from other laboratories. That was where I started discussions with Kipp Weiskopf, a student in Dr. Irving Weissman’s lab. Dr. Weissman is a world-class researcher with a long list of honors and awards; currently, he is the Director of the Institute of Stem Cell Biology and Regenerative Medicine at Stanford. He and his lab members knew a lot about cancer immunology and I knew a lot about small cell, so together we hoped to make a powerful team.

How did the LUNGevity funding enable you to conduct this research?

Our two labs did a bit of preliminary work together but this was a new area of focus for both labs, so we needed funding to get the project underway. We were grateful to receive the LUNGevity award. It gave us two years of funding to do innovative research. We gathered important data that were recently published, and that research allowed us to recently apply for a large federal grant to continue working on improving treatments for patients with SCLC.

What was the focus of your work?

Our immune systems have healthy “vacuum cleaner” cells, called macrophages, which go around eating up bacteria, dead cells, and other things that could make us sick. Most healthy cells in our bodies have “do not eat me” flags, called CD47, that signal macrophages to leave them alone. Every SCLC tumor cell that we tested also had this flag on its surface; it is one of the ways the tumor evades the body’s natural defenses. We wanted to know what would happen if we blocked the CD47 signal on SCLC tumor cells. We hoped that maybe the macrophages would start eating the tumor cells. And that is what happened. We were able to turn these immune system cells into cancer-fighting machines.

What are the next steps?

Our labs want to combine this technique with other therapeutic approaches. For example, we want to know what happens when we combine chemotherapy with an agent that blocks the CD47 “do not eat me” signal on SCLC tumors. Chemotherapy kills cells, which leads to the accumulation of cellular debris and further activates the “vacuum cleaner” macrophages. We hope that by blocking CD47, we can enlist the macrophages in our cancer fight and enhance the overall effects of chemotherapy. In addition, we are also looking for other flags on the surface of SCLC cells that might be good ways to identify or specifically target SCLC cells, with our ultimate goal being the development of drugs that will increase survival rates for SCLC patients.
How has the understanding of squamous cell carcinoma changed over the past decade?

I would actually say the last five-six years have seen incredible progress in our understanding of SCC. Cancer is a sequential process; normal lung cells acquire mutations (alterations in their DNA or the genetic code of the cell) and become cancerous. The first cancer-causing mutation was discovered in the EGFR gene in a subset of adenocarcinomas, in 2004. This opened up new avenues of exploration and new targets to be explored. The next step in testing how these mutations affect the development of SCC is to expand our experimental models to refine the clinical trials that we’re working on. We have now developed mouse models of SCC where we can grow tumors derived from a patient, for example. These patient-derived xenografts (often called PDX models) have revolutionized the way we can test new drugs.

What are some of the new treatment approaches being used or considered for squamous cell carcinoma?

The biggest leap in treatment approaches for SCC so far is the use of immunotherapy. In 2015, the US Food and Drug Administration approved the use of immunotherapy for SCC patients who had progressed after chemotherapy. Now, I can offer immunotherapy to a subset of SCC patients who have not received any prior treatment. We actually have options other than chemotherapy for advanced-stage SCC—something that did not exist even two years ago. The breadth of progress made in targeted therapies for adenocarcinoma, where the one mutation/one drug model holds true, has not been realized in SCC. This is because SCC cells, based on our clinical trial experience, are often not reliably addicted to the effects of one mutation, unlike what you find in adenocarcinoma cells. When you treat SCC cells with a targeted agent, they might, for example, co-opt other pathways that help them grow and escape the growth-blocking agent of the targeted therapy. We are changing our approach and trying combination treatments as we also try to identify new targets for therapy.

How are we learning to use combination therapy for the treatment of squamous cell carcinoma?

Now that immunotherapy has become an option for some advanced-stage patients, we are learning how to combine it with other therapies, including chemotherapy, targeted therapy, and other immunotherapies.
We now know that cancer cells are not islands; they cannot grow without the help of their neighboring cells. The neighborhood of a cancer cell is called the “tumor microenvironment.” Apart from the cancer cell itself, this neighborhood has other cells, such as immune cells. It makes sense, then, to treat the microenvironment as a whole system. Combining immunotherapy with a targeted agent might, as an example, prime the tumor microenvironment, making the SCC cells more visible to the immune system and so susceptible to immunotherapy. These combination trials are ongoing, with many more to come. At the end of the day, I want to have options for each of my patients—options with the highest efficacy and few side effects.

How did you get interested in lung cancer research?

I have always been interested in translational research, and wanted to integrate it into patient care. As a resident at Weill Cornell Medical College, my original career goal had been to become a rheumatologist. Caring for cancer patients changed this, and I switched tracks to oncology, ultimately becoming a fellow at Memorial Sloan Kettering Cancer Center. It was around that period that rearrangements in the ALK gene were discovered in adenocarcinoma patients, this in the wake of work that defined EGFR mutations as targetable. It was an incredibly exciting time for lung cancer patients. We were finally making strides in targeted therapies! I realized that lung cancer research was the perfect integration of my curiosity as a scientist and my love for treating oncology patients as a clinician. I also had the privilege of working with great mentors, including Drs. Mark Kris and Cathy Pietanza at Memorial Sloan Kettering Cancer Center—and the rest is history!

As a thoracic oncologist at Memorial Sloan Kettering Cancer Center, I get to interact with the next generation of translational researchers—and now it is my turn to mentor them.

Did you know that you can fundraise for LUNGevity when you participate in an endurance event?

Join the elite athletes of Team LUNGevity who are running, walking, biking, and swimming to help bring an end to lung cancer! When you complete an endurance event with LUNGevity, you are crossing the finish line not only for yourself, but also for so many who are and will be impacted by lung cancer!

To see endurance event options, visit: www.lungevity.org/events/endurance-events.
Why We Give

An interview with Melissa McParlane, The Dance Connection

Q: How did you first get involved with LUNGevity?

Melissa: My mother was diagnosed in 2010 with small cell lung cancer at age 50 after a number of misdiagnoses. I was her primary caregiver over the 18 months she struggled with treatment and recurrence. She ran a large dance studio, and I learned from her growing up. After I danced professionally, my mother offered me a partnership in the business. We teach over 600 kids a week. When my mother passed away, I wanted to show my students the benefits of giving back to people in need. I found out about LUNGevity’s Breathe Deep Michigan walk, and created the TDC Dancing Divas, a group of dancers who help fundraise for the walk throughout the year.

Q: How do you motivate your students?

Melissa: We look for an activity each month that will appeal to the students. We create gift baskets to be raffled off; we hold restaurant nights and movie events. The money we raise is our team’s donation to Breath Deep Michigan, and we’ve donated about $10,000 each year. This June will be our fourth year attending the walk, and each year we come up with better ways to get involved. The kids get so excited to hear the total of what they raised—that’s the reward.

Q: What impact do you hope your fundraising efforts will make?

Melissa: We live in a “me” world—where we don’t connect to people who are struggling unless it hits home. I hope to show my students that they don’t always have to think of themselves, that there is value in helping people they don’t even know. On a personal level, it’s a way to keep my mom with me while making a difference for people affected by lung cancer.

Why I Volunteer

We spoke with AJ Patel, a stage IV lung cancer survivor and LUNGevity LifeLine support mentor.

Q: How did you first become involved in the LifeLine program?

AJ: Four years ago, I was diagnosed with advanced-stage lung cancer at 47. I was healthy, active, with a family of three kids. I was completely lost, ready to give up completely. When my wife insisted that I get help, I went online and found LUNGevity. I found that I could speak with a LifeLine mentor—someone who had the same experience as mine. I was matched with Matt, and it changed my life.

Q: What was the experience like for you?

AJ: Matt taught me to move on and get into battle mode; not only to be strong, but how. When my scans showed tumors in my brain, Matt was right there next to me. Together we developed a strategy for me. The road ahead began to appear for me. The strength he provided was so powerful that I carry it today.

Q: Why did you become a LifeLine support mentor?

AJ: My lung cancer experience shifted how I look at life. I used to be focused on being successful, measuring myself against others. Suddenly I was the recipient of an outpouring of human compassion from friends, colleagues, and family. I realized that if I could share my strength with others, as Matt had with me, it would help them have a profoundly different view of their disease. What I didn’t expect was how much being a LifeLine mentor would enrich my life.

Q: What would you share with someone living with lung cancer?

AJ: I’m not the cure, but I can show you the way forward to HOPE. We can do this together—you are not alone.

April 23-29 was National Volunteer Week

LUNGevity celebrates the hundreds of volunteers who each year bring their skills, commitment, compassion, and imagination to the Breathe Deep walks, Team LUNGevity, NY and DC Galas, and do-it-yourself events that turn a crowd of individual supporters into a strong lung cancer community. Our research, education, and support programs are only possible because of you.

Thank you, LUNGevity volunteers!
Fall 2016 Breathe Deep and Team LUNGevity Events

Breathe Deep walks across the country are strengthening the lung cancer community! Survivors, volunteers, friends, and family unite to remember loved ones and give encouragement to those affected by lung cancer. This year’s Breathe Deep DC set attendance records, as participants remembered lung cancer patient, advocate, and LUNGevity Board member Jerry Sorkin, who was a founder of the DC walk.

Fall 2016 Breathe Deep and Team LUNGevity events pictured here:

1) Baltimore, MD  7) Kansas City, MO
2) Cincinnati, OH  8) Team LUNGevity-Chicago, IL
3) Washington, DC  9) Nashville, TN
4) Tempe, AZ  10) Arlington TX
5) Somerville, MA  11) New York City, NY
6) Pennsauken, NJ
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For additional information about events near you, visit www.LUNGevity.org/events