

# THE LUNG TIMES

## BOARD AND STAKEHOLDER REVIEW

### MESSAGE FROM BONNIE J. ADDARIO, FOUNDER & CHAIR



**Lung cancer is a GLOBAL epidemic and it requires a GLOBAL effort.**

As baby boomers age, this cancer is predicted to increase significantly in incidence in the next few years. We can and must start to slow that down NOW.

Lung cancer is a complex disease that comes in many forms (small cell, non-small cell, squamous cell, adenocarcinoma, mesothelioma, bronchial adenocarcinoma) and is caused by diverse factors (radon-induced, environmental factors, radiation exposure, etc). The epidemiology of this disease is widespread, affecting many: young adults, men, women, smokers, never smokers, former smokers, mine workers, firemen, teachers, athletes, healthy people, etc. The list is as varied and diverse as the people lung cancer affects.

As we enter the age of genomics the disease becomes even more complicated but more treatable. Through discovery of biomarkers that are unique to patients, we are able to start with each individual patient, identify their unique markers and match them to drugs possibly being used to treat another cancer or disease.

This process is similar to the one being used in a new clinical trial, Lung MAP (The Lung Master Protocol), which will be a game changer in the way clinical trials are designed. In the past clinical trials began with a drug and then looked for patients for whom the drug might provide successful treatment. Now we can and will begin with the patient, identify the biomarker and find a drug.

[tinyurl.com/lungmapPRO](http://tinyurl.com/lungmapPRO)

One patient, one biomarker, one drug...It's personal. With early detection and these treatment options we can make lung cancer a survivable disease. I am sure you have heard me speak of giving patients a "Seat at the Table." ALCF is creating our own TABLE.

We are building an army to get this done, an army of partners who each has a part in this process and can help us to develop a solution and to achieve our goal—to make lung cancer a chronically managed disease by 2023. Please join us...

With much love,

Bonnie

Read About Us  
in the *Journal of  
Thoracic Oncology*

For the first time our research work through the Addario Medical Institute (ALCMI) is featured in the prestigious *Journal of Thoracic Oncology*. I was invited to submit an Op-Ed about our novel INHERIT T790m trial, which focuses on the critical importance of molecular testing to determine if cancer in some families is inherited through their genes. News of our groundbreaking study and initiatives of ALCMI and ALCF will be reaching oncologists and key opinion leaders around the world.

[tinyurl.com/Bjournal](http://tinyurl.com/Bjournal)

**"It always seems  
impossible until it  
is done."**

—Nelson Mandela



## FROM SCOTT SANTARELLA, PRESIDENT & CEO

I am pleased to welcome five new staff members. The addition of these talented professionals in new positions reflects ALCF's and ALCMI's growing commitment and need to advance both current and new initiatives to make lung cancer a chronically managed disease by 2023.

## WELCOME NEW STAFF MEMBERS

Guneet Walia, PhD  
Director of Research & Medical Affairs  
[guneet@lungcancerfoundation.org](mailto:guneet@lungcancerfoundation.org)

Michele Zeh  
Patient Navigation & Services Coordinator  
[michele@lungcancerfoundation.org](mailto:michele@lungcancerfoundation.org)

Melisse Skelton  
Regional Events Manager  
[melisse@lungcancerfoundation.org](mailto:melisse@lungcancerfoundation.org)

Gianna Nannini  
Social Media Coordinator & Team Administrator  
[gianna@lungcancerfoundation.org](mailto:gianna@lungcancerfoundation.org)

Emily Bennett Taylor  
Spokesperson/Patient Advocate  
[gianna@lungcancerfoundation.org](mailto:gianna@lungcancerfoundation.org)

[tinyurl.com/ALCFBIOS](http://tinyurl.com/ALCFBIOS)

**CALL TO ACTION:** Please contact our staff members for more information. Guneet (science and research news); Michele (patient/caregiver assistance); Melisse (events); Gianna (social media posts); Emily (patient advocacy/Young Lung Study)



Please consider donating items to our November "Simply the Best" Gala! We are looking for high-ticket luxury items (ex. destination vacations and/or miles; fine wines; etc) for our Live and Silent Auctions. Many thanks!

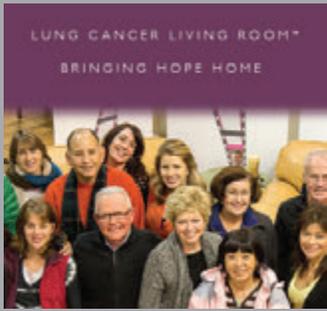
For details, contact:  
[samantha@lungcancerfoundation.org](mailto:samantha@lungcancerfoundation.org)



**REGISTER TODAY FOR A 5K IN YOUR CITY**  
[lungcancerfoundation.org](http://lungcancerfoundation.org)



**TUNE IN LIVE VIA USTREAM TO THE MONTHLY LUNG CANCER LIVING ROOM OR VIEW OUR LIFESAVING VIDEO COLLECTION**  
[lungcancerfoundation.org](http://lungcancerfoundation.org)



## FROM DANIELLE HICKS— PATIENT SERVICES

### 360° Community Hospital Center of Excellence (COE) Program is Growing

Welcome to two Florida hospitals that have recently joined our COE Program to bring multi-discipline, state-of-the-art standard of care to their lung cancer patients and physicians. Memorial Cancer Institute (Hollywood) and Florida Hospital (Tampa) are now part of our growing COE network, with five additional hospitals in Tennessee (3) and Texas (2) in the pipeline to join soon. We are headed towards our goal of having 14 hospitals signed on by the end of 2014.

**CALL TO ACTION:** Is there a hospital in your community that might be interested in becoming a COE? Help ALCF to identify new sites for our network by contacting [danielle@lungcancerfoundation.org](mailto:danielle@lungcancerfoundation.org).

## Smartphone/Tablet APP Empowers Patients NOW!

ALCF doesn't expect patients to be patient when they need critical information. That is why we are leading the way in putting power in patient hands with our Smartphone/Tablet application (APP), the first-of-its-kind for those living with lung cancer. Our APP provides instant access to our Patient Education Handbook, "Navigating Lung Cancer, 360° Degrees of Hope," the Living Room Speaker Series Video Library, Track Your Cancer Tool (to keep all of your info in one place), Glossary, Center of Excellence partnering community hospitals, and more.

**CALL TO ACTION:** Download the APP, show it to others, and send it to any lung cancer patient who can use this valuable tool. Version 4.0 coming soon!



### Coming Soon! "Navigating Lung Cancer, 360° of HOPE" Version 2

**CALL TO ACTION:** Help someone navigate lung cancer with hope and critical information. Stand sidebyside25.com with a lung cancer patient NOW by giving them an ALCF education handbook!

## The Living Room Won't Be on Vacation this Summer!

Mark your calendar for Tuesday, August 19 when renowned pulmonologist Dr. Rex Yung, MD, FCCP, John Hopkins University, Baltimore, MD, will share his expertise about "Pulmonary: Lung Cancer." Be sure to see our complete LR Schedule August-December 2014 and watch videos of past sessions at [lungcancerlivingroom.org](http://lungcancerlivingroom.org).

**CALL TO ACTION:** Let people know about the Living Room series! Invite those in your network to attend in person or remotely.

## Hope is on the Horizon with New Immunotherapy Treatment

When Chris, a nurse, was diagnosed with stage IV non-small cell lung cancer, she was overwhelmed and felt like she was on a roller coaster. That all changed when she found hope in a clinical trial offering a new and novel treatment: immunotherapy.

**CALL TO ACTION:** Do you know someone who needs hope in living with lung cancer? View and share this inspiring video: [tinyurl.com/ChrisNSCLC](http://tinyurl.com/ChrisNSCLC)



## FROM ANDREA PARKS- EVENTS & MARKETING

### THANK YOU Heroes Coast to Coast for Raising Awareness and Funds

Our heroes love to walk, swim, eat, jog, golf, run, party, etc. They are event planners, organizers, fundraisers, cheerleaders and champions willing to do anything (well, almost!) to help fight lung cancer!

### Many thanks to these amazing, compassionate, generous heroes:

- Lung cancer survivor Caren Gorenberg and her family whose annual "Run Amuck with the Duck" in Gainesville, FL raised \$50,000+ in March to support our programs.
- Members of the Tamalpais Aquatic Masters jumped into the pool for the Jon Steiner Memorial Mile in honor of their friend who loved to swim. Miles added up to raising \$2,000!
- Friends and family of Tracy Jill McPhail raised \$2,500 by sponsoring the TJM Run in Vergennes, VT in memory of Tracy who died at age 25.
- Tricia Hartner and Cathy Parese, both survivors, think that holding a pizza parlor party in Wilton, CT is not only a blast but a fantastic way to fundraise for ALCF. How much pizza did they eat to raise close to \$40,000!
- Father and son, Hank Baskett, Sr and Jr, take to the greens in Rancho Palos Verdes, CA to raise funds and awareness with the Hank Baskett Classic Golf Tournament and to celebrate Hank Sr's successful fight against lung cancer.

**CALL TO ACTION:** Grass-roots organizing is a proven and highly successful way to help ALCF build its base of supporters fighting lung cancer. Visit [lungcancerfoundation.org/events/](http://lungcancerfoundation.org/events/) and tap into your personal network of family, friends, neighbors and co-workers and join our growing army of hometown heroes! Organize a creative event on your own in your workplace, neighborhood or school. For ideas, email [samantha@lungcancerfoundation.org](mailto:samantha@lungcancerfoundation.org).

**CALL TO ACTION:** Form a team to participate in our San Francisco Your Next Step is the Cure 5K on Sun, Sept 21 or in one of ALCF's 5K events in a community near you. [lungcancerfoundation.org/events/](http://lungcancerfoundation.org/events/)

## Our Annual Golf Tournament Raised \$150,000+

On June 9, 135 players took to the greens to let lung cancer know that we are going to "Drive It Off the Earth." This annual event (aka "golf reunion"), now in its 9th year, brings back people year after year and also attracts many new foursomes committed to raising funds to benefit ALCF's programs, advocacy and research work. Green Hills Country Club, Millbrae, CA, provides a beautiful setting to enjoy great golf and to share stories of hope. Many thanks to tournament chair and longtime supporter, Ignacio Del Rio of Direct Line, and to Geoffrey's Diamonds and Goldsmith who surprised every participant with a \$500 gift certificate. ALCF is grateful to all of the attendees who made this event such a success! The pictures tell the story. . . [tinyurl.com/golfpics14](http://tinyurl.com/golfpics14)

**CALL TO ACTION:** For those of you with "muscle motivation" to the max, check out one of our endurance events (marathon; Ironman) as a way to help us fight lung cancer! [tinyurl.com/ALCFendurance](http://tinyurl.com/ALCFendurance)



## FROM GUNEET WALIA, PhD— RESEARCH & MEDICAL AFFAIRS

### Revolutionary Funding for Lung Cancer Research: 2014 Young Innovators Team Award

ALCF, in collaboration with the Van Auken Private Foundation, announced a unique new funding mechanism on May 19, 2014, the 2014 Young Innovators Team Award (YITA), a \$500,000 award for teams of young innovators who propose *multidisciplinary, collaborative, out-of-the-box, translational research that has immediate bench-to-bedside translational potential to impact lung cancer patient lives*. This is a revolutionary new funding mechanism targeted to encourage new thinking and leadership skills among young innovators, instilling confidence in them to drive breakthrough, transdisciplinary science under a *collaborative, cross-institutional* paradigm.

ALCF proposes to make the YITA an annual funding mechanism in the coming years in our bid to encourage and involve young investigators in joining our goal to make lung cancer a chronically managed disease by 2023. We will collaborate with family foundations (like the Van Auken Private Foundation) and other donors to eliminate this cancer killer that takes more lives than prostate, breast and colon cancer combined. Read Press Release: [tinyurl.com/ALCFyita](http://tinyurl.com/ALCFyita)

**CALL TO ACTION:** For details and to brainstorm ideas on how we can collaborate on a Young Innovators Team Award, contact [guneet@lungcancerfoundation.org](mailto:guneet@lungcancerfoundation.org).

## Lung Master Protocol (MAP) Clinical Trial Leads Way in Revolutionizing Trial Process

ALCF is collaborating in a unique, first-of-its-kind public-private partnership to revolutionize the way that clinical trials are conducted. We will be joining with 10 other public-private entities to conduct a multi-drug, multi-arm, biomarker-driven clinical trial for patients with advanced squamous cell lung cancer. For the first time a trial will begin with the focus on the patient and personalize therapy to the mutations in their tumors rather than beginning a trial focused on testing a chosen drug in a non-specific patient population. The Lung Map Clinical Trial is a game-changing process and will revolutionize the way clinical trials are conducted, leading the way to more rapid drug development and approval for patients.

**CALL TO ACTION:** Share information about the Lung Master Protocol Clinical Trial with anyone you know who has advanced squamous cell lung cancer. Read Press Release: [tinyurl.com/lungmapPRO](http://tinyurl.com/lungmapPRO)

## Launching a Lung Cancer Patient Portal on ALCF Website

ALCF proposes to launch a Patient Portal on its website this summer to provide the latest information on new lung cancer treatments/therapeutics, diagnostics, prognostics and exciting developments in research that have immediate impact on lung cancer patient lives. Our goal is to empower patients to take on their disease armed with the latest and best scientific knowledge. We will also launch a monthly email newsletter that will provide a summary/quick recap of developments in the past month. We encourage patients, caregivers, physicians and nurses to watch for this exciting new service.

**CALL TO ACTION:** Please share your suggestions/comments about what you would like featured on the Patient Portal. Contact [guneet@lungcancerfoundation.org](mailto:guneet@lungcancerfoundation.org).



## FROM STEVEN YOUNG—ALCMI New Clinical Study Aims to Investigate the Genomics of Young Lung Cancer

The Addario Lung Cancer Medical Institute (ALCMI) is putting the spotlight on lung cancer in young adults with a new study, the Genomics of Young Lung Cancer, to understand why the disease occurs in young adults, who quite often are athletic, never smokers and do not exhibit any of the known lung cancer genetic mutations. ALCMI, a patient-centric, international research consortium and partner of ALCF, is facilitating this first-of-its-kind, multi-institutional, prospective genomic study in order to identify new genome-defined subtypes of lung cancer and accelerate delivery of more effective targeted therapies. Read article featured in the San Francisco Chronicle: [tinyurl.com/youngSF](http://tinyurl.com/youngSF)

"It's heartbreaking when you meet young adults with lung cancer, who should have their full lives ahead of them but instead are fighting for their lives because of the lack of lung cancer treatments," said Bonnie J. Addario, stage 3B lung cancer survivor and founder of ALCMI and the ALCF. "This groundbreaking study will investigate why never-smoker adults under the age of 40 are getting lung cancer and whether they have a unique cancer subtype, or genotype, that can be treated differently."

Our evolving understanding of the disease and new molecular tools suggest that young age may be an under-appreciated clinical marker of new genetic subtypes. An important goal for this research study is

to reveal new lung cancer sub-types requiring distinct treatment strategies.

"Leveraging this study as a proof of principle, ALCMI is also characterizing other specific patient populations to support emerging data that lung cancer diagnostic and therapeutic interventions are more effective when individualized, and personalized approaches are brought to bear," says Steven Young, President and COO of ALCMI, who also points out that this study represents a unique public-private collaboration between the ALCMI consortium and Foundation Medicine, Inc.

The Genomics of Young Lung Cancer study is centrally managed by ALCMI while the Principal Investigator (study leader) is Barbara Gitlitz, MD, Associate Professor of Medicine, University of Southern California, Norris Comprehensive Cancer Center.

"This study lays the groundwork for discovery of novel targetable genotypes as well as heritable and environmental risk factors for lung cancer patients under 40," Dr. Gitlitz said.

Other investigators include Geoffrey Oxnard, MD, (Dana-Farber Cancer Institute, Harvard Medical School), David Carbone, MD, PhD (The Ohio State University), and Giorgio Scagliotti, MD, PhD and Silvia Novello, MD (both at the University of Torino in Italy). Patients may enroll in the study regardless of where they live and will not need to travel to any of the above institutions.

**CALL TO ACTION:** Please extend thanks to the Genentech Foundation for their project support, and help us to extend patient lives by providing funding for this innovative study.

For more information about the study, please contact [syoung@alcmi.net](mailto:syoung@alcmi.net)/[www.alcmi.net](http://www.alcmi.net)

**LEARN THE FACTS ABOUT LUNG CANCER:**  
[tinyurl.com/ALCFfacts](http://tinyurl.com/ALCFfacts)



## FROM DANI GASPARINI PHILANTHROPY CORNER

### Stay Involved, Stay Connected

Penelope lost her mom in December 2013, but for her family the fight isn't over. She stays in touch with ALCF by attending our monthly Living Room ([lungcancerlivingroom.org](http://lungcancerlivingroom.org)) sessions and sharing with others the critical importance of her continued advocacy to raise awareness about the disease that has taken the lives of three family members, her mother and two aunts.

Although many have lost their fight, many are still living with the disease and many more will be diagnosed in the future. That is the reality of lung cancer, the world's number one cancer killer.

Our thanks to all of the generous family, friends and caregivers who have made donations in memory of a loved one. We share your sadness, but we also celebrate you for supporting ALCF's programs and services that help others affected by lung cancer.

**CALL TO ACTION:** ALCF offers many rewarding ways to stay connected and engaged in fighting lung cancer AND to continue to help patients and families. Contact [dgasparini@lungcancerfoundation.org](mailto:dgasparini@lungcancerfoundation.org) for more information. For ideas to hold an independent fundraiser, contact [jhughes@lungcancerfoundation.org](mailto:jhughes@lungcancerfoundation.org). For upcoming events: [lungcancerfoundation.org/events/](http://lungcancerfoundation.org/events/)

### Stewarding Resources

Many thanks to our corporate, academic, non-profit and individual partners for their commitment and willingness to share their time, talents and treasure with ALCF! These generous partners have supported our programs and services to educate, empower and raise awareness and funds to fight lung cancer. Thank you for helping us to reach our goal of making lung cancer a chronically managed disease by 2023!

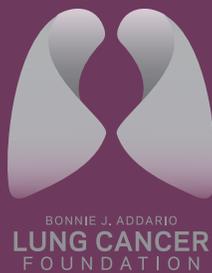
**CALL TO ACTION:** Do you know staff or board members affiliated with any companies and/or venture philanthropists who might be interested in supporting ALCF? We would love to talk with them! Contact Dani Gasparini, EVP Strategic Initiatives & Philanthropy, 650.598.2857.

## Include Us in Your Estate Plans and Save a Life

Making a planned gift to ALCF today is a rewarding and meaningful way for you and your family to touch the lives of hundreds of thousands of lung cancer patients in the future and to leave a lasting legacy to patients and programs in need of your support. Legacy giving brings both personal and financial benefits, tax advantages, and the knowledge that through your generosity and planning for tomorrow, you are helping ALCF to have a significant impact on the survival of lung cancer patients.

**CALL TO ACTION:** To learn about the benefits of estate planning, tax advantages of Qualified Charitable Distributions (QCDs), and the many options (Securities, Life Income Gifts, Charitable Gift Annuity, Charitable Remainder Trust, etc.) you have to leave a legacy, contact: Dani Gasparini, EVP Strategic Initiatives & Philanthropy, 650.598.2857.

See overview on planned giving, benefits and tax advantages: [tinyurl.com/ALCFpg](http://tinyurl.com/ALCFpg)



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