



PARTNERS IN PROMISE

DECEMBER 2016

Your generosity in partnering with us provides promise and progress in our commitment to make lung cancer a chronically manageable disease.

EXPANDING ACCESS TO TREATMENT FOR ALL LUNG CANCER PATIENTS

“Cancer is a disease that can affect anyone, but it doesn’t affect everyone equally. Statistics show that some populations and people who lack access to health care are more likely to develop cancer—and die from it—than the general population.”

Richard C. Wender, M.D., American Cancer Society

The Bonnie J. Addario Lung Cancer Foundation (ALCF) wants to ensure that ALL lung cancer patients, regardless of where they live or their socio-economic status, have access to personal, multi-disciplinary care. The “Centers of Excellence” (COE) Program, a nationwide network of community hospitals, was created to address this need as 80% of cancer patients are treated in the community setting. COEs deliver a patient-centered standard of care similar to the specialty care provided at leading academic institutions.

Our goal is to reach 10,000+ lung cancer patients and caregivers within the COE network of 13 sites this year with greater numbers reached as our network grows.

**COE Champion
Dr. Luis E. Raez (#172)
of the Team Memorial
Cancer Institute
Warriors shares
enthusiasm and
hope with patients,
families, friends and
colleagues at “Your
Next Step is the Cure”
5K, Hollywood, FL.**



“CENTERS OF EXCELLENCE” RAISE THE BAR FOR LUNG CANCER TREATMENT AT COMMUNITY HOSPITALS

The COE Program is the first-of-its-kind to reach vulnerable lung cancer patient populations nationwide, including uninsured, non-English speakers, indigent and minorities.

- El Camino Hospital, Mountain View, CA
- Gene Upshaw Memorial Tahoe Forest Cancer Center, Truckee, CA
- Dignity Health Cancer Institute/Mercy San Juan Medical Center, Carmichael, CA
- Memorial Cancer Institute, Hollywood, FL
- Florida Hospital, Tampa, FL
- Baptist Memorial Hospital, Memphis, TN
- St. Thomas Health West, Nashville, TN
- First Health Moore Regional, Pinehurst, NC
- Leo W. Jenkin Cancer Center, Greenville, NC
- Gibbs Cancer Center, Spartanburg, SC
- OSF St. Francis, Peoria, IL
- Texas Oncology Presbyterian Cancer Center, Dallas, TX
- Gunderson Health, LaCrosse, WI

“The ALCF COE Program raises the bar for community hospital oncology,” says **Dr. Luis E. Raez**, Medical Director, Memorial Cancer Institute (MCI), Hollywood, FL. “Community hospitals can now provide and deliver the best lung cancer care available so patients do not have to travel to find first-class treatment.” MCI reaches and serves significantly more Hispanic patients with quality multi-disciplinary care than community or academic hospitals nationally, with nearly 80% of patients coming from within 10 miles of the hospital.

LEARN MORE OR NOMINATE YOUR LOCAL CENTER AS A COE SITE:

lungcancerfoundation.org/patients/centers-of-excellence/
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PATIENT REGISTRY USES BIG DATA TO ADVANCE RESEARCH

Because sharing information and robust data is key to understanding and treating cancer, the Bonnie J. Addario Lung Cancer Foundation (ALCF) and the American Lung Association (ALA) have teamed up to create the Lung Cancer Registry (The Registry).

More than 1.8 M people in the world are diagnosed with some form of lung cancer every year. Patient experience is an important tool in identifying patterns that could lead to better diagnostics and treatments, new therapies and ultimately better outcomes. By participating in The Registry, patients are part of a global effort to provide researchers with data to help them better understand the disease.

Patients will also benefit by being able to see and compare their personal information with patients worldwide, see how treatment might be tailored to their individual needs, and hear about clinical trials relevant to their disease state.

Patients and their active participation in the care continuum are part of the solution in making lung cancer a survivable disease. Because their data holds great promise and is key to progress, our goal is to have 10,000 patients enrolled by the end of 2019. One of the patients participating is **Alex Charpentier**,

At age 47, marathoner Alex Charpentier seems an unlikely candidate to have been diagnosed with lung cancer, but then again, not really. Anyone can get lung cancer.

In 2014 Alex left corporate America to follow a life-long dream of going to culinary school and in March 2016 she graduated with a degree in culinary arts. Three months later she received some grim news.

“I am one of the alarmingly growing number of non-smoking women to be diagnosed with lung cancer. Being told that you have stage 4, inoperable, incurable lung cancer that has spread from your lungs to your pleura fluid, bones and lymph nodes due to a genetic mutation, you know that your prognosis cannot be good,” says Alex. “But what I also know is that Alex Charpentier has never had

*Alex Charpentier
(with son Gabriel)*

“You don’t know how strong you are, until being strong is the only choice you have.”



lung cancer, so there are no published statistics on my life expectancy. I am not a statistic, I am a fighter.”

Alex is now on a mission to raise awareness and money for research, teaming up with her fitness studio in Austin, TX to hold “Burn Away Cancer,” a highly energetic and creative one-day fundraiser for ALCF where the gym donated one cent for every calorie burned. And with her son at her side, Alex also ran the Las Vegas Rock ‘n Roll Half-Marathon in November as part of the ALCF Endurance Team, “A Breath Away,” raising funds to support patients fighting lung cancer today and ones who will be fighting tomorrow.

LEARN MORE ABOUT THE PATIENT REGISTRY:
lungcancerregistry.org

Contact: Danielle Hicks, Associate Executive Director, Patient Services & Programs
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PATIENT PROGRAMS EXTEND HOPE TO HOMES AROUND THE WORLD

Since ALCF held its first Living Room (LR) Patient Education, Support Group & Speaker Series in 2009, our monthly programs have streamed hope to the living rooms of 850,000+ people in 145+ countries worldwide.

For patients, survivors, caregivers and families the LR is the place to be for getting up-to-date information from experts, sharing personal stories, and supporting, interacting and connecting with others in the fight against this disease. With availability 24/7 on our website the LR Series—combined with ALCF's Patient Education Handbook in English, Spanish and Chinese—ensures that hope is never off-line for those living with lung cancer.

For the **Schiffman family**, the LR series was always a “friends and family affair.” For four years Neil Schiffman, diagnosed with Stage 4 lung cancer in 2011, was a familiar face and an empowering, hope-filled patient voice at LR sessions at ALCF in San Carlos, CA. He and his wife Evy rarely missed a session nor did friends and family scattered across the U.S. Three-thousand miles away in a living room in Sarasota, FL, Neil's 90-year-old mother watched through livestream. Seeing Neil participate in the monthly programs was a high-point for his mother, helping her to understand the disease and what her son was going through.

When Neil died in 2015, friend **Kelly Hudson** wanted to do something special in his memory. “Giving a monthly donation to ALCF is a meaningful way for me to keep his voice alive as a patient, fighter and advocate,” says Kelly. “Like the monthly LR Series that so benefited Neil and provided a hopeful forum for him to connect and learn with others, I feel that my monthly donation will pay forward his hope and the work and commitment he had to support ALCF's patient programs and help others.”



Left to right: Evy Schiffman, Tilmin & Kelly Hudson. For the Hudson sisters, giving to ALCF is a family affair. Both Tilmin & Kelly participate in ALCF's San Francisco 5K as part of Team Neil SoloZip. Kelly is a monthly donor. Tilmin fundraises for the 5K team & doubles her efforts with her company's matching donation.

UPCOMING ALCF EVENTS

LUNG CANCER LIVING ROOM

Tue, Dec 20, Patient Roundtable & Holiday Celebration

Tue, Jan 17, Patient-Driven Data & Patient Registries

Tue, Feb 21, Liquid Biopsies, Circulating Tumor Cells, DNA & Molecular Testing

Tue, March 21, Patient Roundtable, What is the one thing you wish people knew about lung cancer?

“YOUR NEXT STEP IS THE CURE” 5K WALK/RUN

Sun, Feb 12, San Dimas, CA

Sun, Feb 26, Tempe, AZ

Sat, Apr 22, Sacramento, CA

RUN AMUCK WITH THE DUCK

Sat, March 4, Gainesville, FL

LEARN MORE ABOUT PATIENT EDUCATION/SUPPORT PROGRAMS:
lungcancerfoundation.org/patients/support/
 Contact: Danielle Hicks, Associate Executive Director, Patient Services & Programs
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PATIENTS DRIVE RESEARCH FOR ROS1 STUDY BY ALCF AND ALCMI

It is devastating enough to be told that you have lung cancer, but it is even more devastating to hear that you have a rare molecular subtype of cancer that doesn't have many treatment options. This news, however, has not deterred **Lisa Goldman** or **Xiuting Chen**.

"In January 2014, after several frustrating months of repeated doctor visits and misdiagnoses about a nagging cough, a pulmonologist ordered a CT scan," says **Lisa Goldman**, age 43. "He told me that I had Stage 4 lung cancer. And further testing revealed a ROS1-fusion, a relatively rare subset of cancers it is diagnosed in, typically accounting for 1–2% of most cancers."



Shortly after diagnosis Lisa came to ALCF seeking information and becoming a strong advocate for ROS1 research. Because of the input and advocacy of Lisa and other patients ALCF and its partner organization, the Addario Lung Cancer Medical Institute (ALCMI), have launched a global, pan-cancer ROS1 Study that is looking at the causes of ROS1-fusion driven cancers, and building preclinical models to study the biology of the disease and its response to unique new treatments.

"ALCF is attacking lung cancer through a 'slices of the pie' approach. We understand that lung cancer is not one disease but a collection of diseases with multiple causes and underlying unique genomic alterations, each of which needs to be treated differently," says Guneet Walia, PhD, ALCF

Senior Director, Research & Medical Affairs. "The ROS1 Study addresses the disease from the perspective of the genomic alteration driving the cancer, regardless of the cancer's anatomical tissue of origin." The study has enrolled 120 patients from 11 countries with different cancer types (i.e. lung, colorectal, ovarian, gastric, etc), all with the ROS1-fusion driving their tumors. All patients are driven to help researchers increase understanding of their "slice of the cancer pie" and ROS1 participants are actively fundraising for this study. Next steps will include identifying 10 patients as representatives of this international group to form the ALCF ROS1 Patient Advisory Board.

In 2014 **Xiuting Chen**, now age 29, came to Seattle from China with her husband, a cancer research fellow. Within six months, she was hospitalized and diagnosed with ROS1-fusion positive Stage 4 lung cancer.

"I was a junior resident physician with three years of cancer research experience in China. After settling in Seattle, I studied hard for the U.S. Medical Licensing Exam so that I could continue being a physician," says Xiuting Chen. Hit with such a devastating diagnosis, she worried that she would be missing all the important events that are supposed to happen in life—having a family, being a mother, pursuing a career.

She asked herself the question, "Would it be impossible for me to have a regular life?" Her answer: "My husband's love, my doctors' help and the research of scientists help me to conquer all the negative emotions and difficult times," she says. "Fortunately I am on a targeted treatment, crizotinib, and am responding very well. I have a chance to build my castle in the world of cancer. I cherish the people I love. I continue to learn English. Life is still fulfilling and beautiful."



LEARN ABOUT AND/OR PARTICIPATE IN THE ROS1 STUDY:

lungcancerfoundation.org/patients/ROS1/

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