

Bonnie J. Addario Lung Cancer Foundation & The Addario Lung Cancer Medical Institute



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Mission

The Bonnie J. Addario Lung Cancer Foundation (BJALCF) is one of the largest philanthropies devoted exclusively to eradicating lung cancer through research, early detection, education, and treatment. Established in 2006, the foundation works with a diverse group of physicians, organizations, industry partners, individuals, survivors, and their families to identify solutions and make timely and meaningful change. BJALCF's ultimate goal is to turn lung cancer into a survivable, manageable chronic disease within 10 years.

Two years after BJALCF began, the Addario Lung Cancer Medical Institute (ALCMI) was created to connect the top thought leaders, scientists, researchers, and physicians worldwide to lead and empower patients toward better treatment options. ALCMI's mission is to help transform lung cancer into a survivable disease via improved understanding of tumor biology, identifying and validating druggable targets, elucidating molecular bases for acquired drug resistance, and accelerated development/delivery of targeted therapies via early-phase clinical trials.

Strategy/Approach

ALCMI and BJALCF are committed to improving the standard of care for patients diagnosed with lung cancer and people yet to be diagnosed. Both organizations recognize the vital importance of molecular testing to develop personalized therapies, and of translating laboratory science into personalized care for patients and their families.

- **BJALCF** believes that cancer treatment is proceeding rapidly toward the era of individualized medicine, where decisions will be based on the individual molecular characteristics of each patient's tumor. It seeks to advance knowledge about the genetic events that characterize each patient's tumor, and find new ways to develop combinatorial targeted therapies to eradicate this disease through focused grant giving. BJALCF's funding decisions are made with the goal of driving research on lung cancer forward in three areas:
 - *Early detection*
 - *New and innovative therapies*
 - *Basic research*

- **ALCMI** links researchers via shared infrastructures and prioritized research programs, including standardized biorepositories, data systems, contracts, study protocols, and ongoing collaboration discussions among scientists. Its programs aim to:
 - *Address scarcity of well-annotated, high-quality tissues.*
 - *Improve understanding of the molecular/genetic causes and mechanisms of lung cancer.*
 - *Identify and validate optimal molecular targets and facilitate development of effective, targeted therapies.*
 - *Accelerate advancement of promising compounds/agents from the laboratory to the clinic.*

Research Portfolio

BJALCF focuses on funding only immediate results-oriented projects or programs that promise to catalyze progress through early detection, genetic testing, drug discovery, and patient-focused outcomes.

ALCMI's strategic research goals include:

- Establish centralized research infrastructures
- Accelerate the understanding of the molecular/genetic causes and mechanisms
- Identify weaknesses in the lung cancer cell's defenses to help develop effective, targeted therapies
- Deliver the right treatments to the right patients

To achieve these goals ALCMI has developed the following:

- **Collaborative Advanced Stage Tissue Lung Cancer Network (CASTLE) Network Study** – Conducts laboratory tests and research on cancer tissue and blood samples donated by people diagnosed with lung cancer. It maintains these specimens in a centralized database and facilitates integration with molecular assays and other laboratory studies.
- **Correlative Science Study** – Enables longitudinal detection and monitoring of mutations in blood, and correlation with clinical outcomes in lung cancer patients.
- **Molecular Science Studies** – Evaluate the prevalence and prognostic value of certain lung cancer-related biomarkers in samples from patients enrolled in observational biomarker and therapeutic clinical trials to establish a translational biomarker database. The results of these studies will help to guide clinical study designs as well as inform physicians and patients of the genetics and biology of their particular tumors.

- **Genomics of Young Lung Cancer Study**—Determine whether cancer in patients under 40 contains a distinctive spectrum of genetic mutations. This may indicate the need and opportunity for individualized management approaches for young patients.
- **Shared Infrastructures**—The ALCMI Data Repository enables centralized biological specimen tracking through the course of treatment/outcomes to comply with regulations. ALCMI also acts as a lead negotiator for research agreements internally and externally, to significantly reduce the complexity of multiparty collaboration agreements, thereby accelerating the process.

Partnership Practices

BJALCF offers the opportunity for like-minded organizations to operate under its 501(c)(3) status. By becoming an affiliate, an organization can set up a unique fund and raise the much-needed funding for lung cancer, like the Mae’s Breath Foundation in New York, the Baretta Family in Colorado, or The Fighting Barry Foundation in Maryland have done. This [affiliate program](#) allows organizations to become a partner of BJALCF without having to become their own 501(c)(3) organizations, and accelerates the movement and mission to eradicate lung cancer.

BJALCF partners with biotech and pharmaceutical companies. Through its grant programs, it supports companies like 20/20 Gene Systems, Inc., which was awarded a grant to develop the first routine blood test for lung cancer.

ALCMI also partners with biotech and pharmaceutical companies. For example, Clovis Oncology and Roche Molecular Systems are developing a PCR-based diagnostic utilizing (in part) CASTLE tissue samples and data. Clovis Oncology is also partnering with ALCMI to conduct a drug clinical trial in patients selected using the PCR test. Other partners include Response Genetics and Bodesix with which ALCMI is working to expand the molecular testing panel and broaden patient access, and Boehringer Ingelheim, which is supporting efforts to promote genetic biomarker testing.

Financials

BJALCF is a 501(c)(3) tax-exempt nonprofit organization. The most recent financial information available is from 2010.¹

Year ending 12/31/10:

- Revenue: \$1,502,895
- Assets: \$604,119
- Grants paid: \$515,090
- Gifts received: \$449,399
- Expenditures: \$1,317,641

ALCMI is a 501(c)(3) tax-exempt nonprofit organization. The most recent financial information available is from 2011.²

- Revenue: \$522,891

- Assets: \$19,031
- Grants Paid: \$0
- Gifts received: \$522,806
- Expenditures: \$544,002

Key Accomplishments

BJALCF:

- Raised more than \$10 million for lung cancer research since its founding in 2006.
- Funded various projects over the past three years totaling more than \$1.8 million.
- Initiated various high-profile educational campaigns, public service announcements, and events with celebrities such as Maroon 5 and Hank Baskett.

ALCMI:

- Identified and recruited many of the world’s leading lung cancer researchers and academic centers to work together to defeat lung cancer in close collaboration with clinical researchers and practitioners in the community setting.
- Established consensus among the ALCMI scientists and established shared translational research infrastructures (biobanks, data systems, centralized project development/management), enabling innovative studies such as CASTLE.
- Each research project must aim for demonstrable, short-/mid-term benefit for lung cancer patients; i.e. the “measures of success” of ALCMI are strictly tied to improved patient outcomes as opposed to the number of resultant scientific publications.

Leadership

The Bonnie J. Addario Lung Cancer Foundation is governed by an **Executive Board**, supported by a **Medical Advisory Board** and **Scientific Advisory Board**, and managed by a California-based **staff**. The Addario Lung Cancer Medical Institute is governed by a **Board of Directors** and a **Scientific Leadership Board** and managed by a Connecticut-based **staff**.

- **President and CEO, BJALCF:** Scott Santarella, ssantarella@lungcancerfoundation.org
- **EVP, Strategic Initiatives, BJALCF:** Dani Gasparini, dgasparini@lungcancerfoundation.org
- **President & COO, ALCMI:** Steven Young, syoung@alcmi.net
- **Director of Clinical Operations, ALCMI:** Alicia Sable-Hunt, RN, MBA, asable-hunt@alcmi.net

¹ Information obtained from Foundation Center Directory, <http://fconline.foundationcenter.org>, May 2012.

² Information obtained from GuideStar directory, www.guidestar.org, February 2014