

# The voice of the patient: a venue for all of our voices in *Annals of Translational Medicine*

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Submitted Jan 20, 2015. Accepted for publication Jan 20, 2015.

doi: 10.3978/j.issn.2305-5839.2015.01.29

View this article at: <http://dx.doi.org/10.3978/j.issn.2305-5839.2015.01.29>

From January 15, 2015, *Annals of Translational Medicine* (ATM) is endorsed by the Bonnie J. Addario Lung Cancer Foundation (ALCF).

With the same ideal, ATM will launch a special column named “the Voice of the Patient” in the first quarter of 2015 as an outcome of the academic collaboration with ALCF.

“Since my diagnosis I have constantly heard the term ‘translational research’, meaning from the bench to the patient. Transformational research is from the patient to the bench and back to the patient. We must add the patient to the process and understand that they are the beginning and the end of the process”, said Mrs. Bonnie J. Addario, Chair of the column “the Voice of the Patient” and founder of the ALCF.

The goal with this column is global patient survival advanced through inviting stakeholders—clinicians, physicians, researchers, patients, life science specialists—who believe that we can and will accomplish this goal to write articles and share what they are doing to make this a reality. We need to educate each other about processes that work. To accomplish this, we must open up our rich silos of information and share our knowledge across all disciplines and nations. This column is a venue for all of our voices and a way for you to have a seat at the stakeholder table.

## 2015 partnership proposal of ALCF

The ALCF ([www.lungcancerfoundation.org](http://www.lungcancerfoundation.org), Figure 1), an Internal Revenue Service (IRS) approved 501(c)3, focuses on the immediate goal of increasing survival rates and providing hope to those suffering with lung cancer. ALCF

concentrates on research, patient support, education, empowerment, awareness and advocacy. We provide patients and families a road map to guide them and a support system to anchor them. In 2008, ALCF’s partner organization was born, Addario Lung Cancer Medical Institute (ALCMI), as a result of gathering world-wide key opinion leaders (KOLs) together. With KOLs understanding that if “money were no object”, what would be the one thing ALCF could facilitate to change the lung cancer landscape, the answer was to create a non-biased, collective, cooperative, open biorepository from which anyone could study.

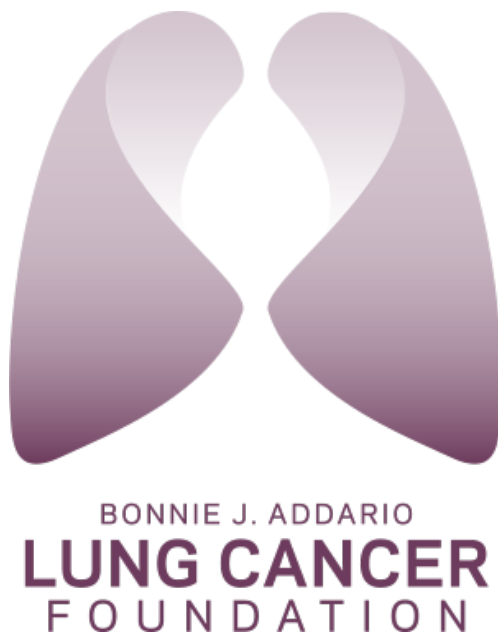
## The mission/goal/vision of ALCF

### Mission: increase survival

Patients fighting lung cancer today and those diagnosed tomorrow are at the heart of ALCF’s mission. Because this disease is the number one cancer killer worldwide annually, our most urgent imperative is to dramatically increase patient survival rate NOW.

### Goal: transform lung cancer into a chronically managed disease by 2023 and ultimately a survivable disease

ALCF will achieve our goal through providing programs and support services to empower and educate patients and families, funding cutting-edge research, raising public awareness and advocacy. We believe that personalized medicine is the gateway to success and patients must be given a seat at the table where treatment and care decisions are made.



**Figure 1** The Bonnie J. Addario Lung Cancer Foundation (ALCF).



**Figure 2** Mrs. Bonnie J. Addario.

***Vision: be the global leader and largest source of non-profit funding dedicated to fighting lung cancer***

ALCF will make our vision a reality by building strategic collaborations and partnerships with leaders in oncology, technology, science, medicine, and philanthropy. We will

power progress by involving all stakeholders: patients, donors, clinicians, pharma, biotech, payers, government, policy makers, public and private enterprise.

### **Bonnie's story**

Long before its official start date, a single diagnosis led to the founding of the ALCF when in 2004 Bonnie (*Figure 2*) was diagnosed with lung cancer. At the age of 56 she was a wife, mother and grandmother, the president of Olympian Oil Company and the Commercial Fueling Network, and one of 1.4 million people worldwide and 225,000 Americans newly diagnosed with lung cancer every year. Faced with a 5-year lung cancer patient survival rate of 15.9%, a statistic that has not significantly improved in 40 years, and a 5% survival rate for a stage IIIb lung cancer patient, which was Bonnie's diagnosis, the situation as told by these numbers was daunting and discouraging. Following a 14-hour surgery to remove one lobe, radiation and chemotherapy treatments that invaded her formerly predictable world, Bonnie became a lung cancer survivor with a new purpose in life.

After her diagnosis, Bonnie became active in local lung cancer programs and quickly became frustrated with the lack of a leading patient voice, progress in lung cancer treatments, and overall survivorship. In 2006, Bonnie combined her business acumen with her desire to impact lung cancer care today, the result—the ALCF.

ALCF's goal is urgent—to significantly improve the inexcusably low survival rate of lung cancer patients. With Bonnie's vision and support of her family, the lung cancer community and you, ALCF has become one of the largest sources of non-profit patient-focused funding dedicated to changing lung cancer from a terminal diagnosis to a chronically managed disease by 2023, ALCF's vision and 10-year goal that was announced in 2013.

Having become a unifying voice among patients and thought leaders, establishing unique patient-oriented programs, a novel research consortium, and national outreach activities, Bonnie is turning to the international lung cancer community to work collaboratively towards personalized medicine/therapies.

*"The key to unlock the code to cures... resides in the patient. Currently their participation in clinical trials and specimen donations for research is very, very low. Patients must be valued and given a 'seat' at the table and a 'voice' in the conversation where all decisions are being made about their survival. If they are added to the 'solution' process we will be able to move much*

*faster in finding cures for all diseases”.*

*“We are committed to involving our patients in every aspect of our work to cure lung cancer. With the patient in the center of the cancer paradigm, we can create ‘transformational research’ care that begins with the patient, leads to research, and rapidly returns*

*new treatments to the patient.”—Bonnie.*

## Acknowledgements

*Disclosure:* The author declares no conflict of interest.

**Cite this article as:** Li GS. The voice of the patient: a venue for all of our voices in *Annals of Translational Medicine*. Ann Transl Med 2015;3(2):28. doi: 10.3978/j.issn.2305-5839.2015.01.29