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Maryland Patient with Lung Cancer Advises Newly Diagnosed Patients: Be Your Own Advocate

Patient perspectives provide context for research advances discussed at the IASLC 2020 North America Conference on Lung Cancer

Silver Spring, Md, resident Frances Beard was diagnosed in February 2013 with lung cancer during a routine chest x-ray for an upcoming elective surgery. As an individual who never smoked, Beard was surprised by the diagnosis, but between 15 and 20 percent of all lung cancers occur in those who have never smoked, according to the International Association for the Study of Lung Cancer.

The newly retired organizational development consultant had experienced no lung cancer symptoms, but the x-ray showed a growth abnormality in one of her lungs. She was referred to a thoracic surgeon at Johns Hopkins Hospital and scheduled surgery to remove the tumor in her lung. However, the surgeon discovered metastases in the pleural lining of her lung and mediastinum and was unable to successfully remove the affected parts of her lung. Instead, a VATS procedure was done and helped to determine that the cancer was *EGFR*-positive stage IV non-small cell lung cancer (NSCLC). Because of targeted therapy Ms. Beard began within several weeks after the failed surgical attempt, and a newer targeted therapy that was needed two and a half years later, her quality of life has improved beyond all reasonable expectations since diagnosis. The cancer in her lung has remained stable for five years now on her current targeted therapy.

Although the metastases are still present, Ms. Beard is deeply grateful for more than seven years of survivorship, thanks to newer therapies, having found excellent medical providers and the love and support of a loving family and a host of friends. She demonstrates her gratitude within the lung cancer community by advocating for lung cancer patients and serving with LUNGeivity as a Lifeline Support contact, where she can help by lending support to newly diagnosed patients with lung cancer. She was inspired by her own Lifeline Support partner.

“There’s something remarkable about connecting with people. I felt alone in the diagnosis with lung cancer — many people know someone with many types of cancer but not with lung cancer so finding a community of people with similar stories has been exceedingly therapeutic,” said Ms. Beard. Based on her early experiences, Ms. Beard advises new patients with lung cancer to not rush into their first treatment option but to do their own research and get more than one opinion.

“Be your own advocate,” she stressed.

Uniting Separate Perspectives into One Story

So many patients with lung cancer have similar stories to that of Frances Beard, beginning with the surprise at diagnosis to a gradual understanding of the underlying pathogenesis of the disease. At the IASLC 2020 North America Conference on Lung Cancer this Friday and Saturday, Ms. Beard’s perspective opens the targeted therapy portion of the program, in which new biomarker-driven therapies will be discussed. There will also be a presentation by two patient research advocates who are living with lung cancer themselves and have benefited by the development of recently developed targeted therapies. These advocates will be talking about the oncogene patient groups that have formed to support, educate, empower patients while driving research into their own disease.

Improved knowledge about genetic mutations and the immune system has led to improved treatments and more precision medicine approaches, which in turn have led to people with lung cancer living longer. Up until the late 1990s, there were no patient advocate organizations in the United States dedicated solely to lung cancer. At that time, lung cancer was seen as a “smokers’ disease,” and treatments were extremely limited. Although stigma is still felt by many patients from differing backgrounds and with different life experiences, therapeutic advancements are moving extremely rapidly, providing more opportunities for patients and advocates to provide insights on survivorship issues, clinical trial participation and design, and research endpoints that are meaningful to the lung cancer community.

The conference will provide research updates in the forms of data presentations given by the multidisciplinary experts in the field and downloadable/searchable posters. A special focus on the patient’s perspective and how patients have benefited from recent research will be evident in the patient vignettes, and patient research advocate Ms. Jill Feldman will highlight the impact on patients of the recent paradigm shift in early-stage disease.

Related Resources:

Ending Stigma in Lung Cancer: The IASLC Participates in a Collaborative Summit Held by the National Lung Cancer Roundtable

By Jill Feldman; Nicholas R. Faris, MDiv; and Graham W. Warren, MD, PhD

In healthcare, stigma could be any sociocultural norm that prevents a patient’s access to or experience of high-quality care. With lung cancer in particular, patients often feel stigmatized by clinicians, patients, family, friends, and within themselves as being responsible for causing their lung cancer or for not caring about their diagnosis. False perceptions, delays in diagnosis, lack of knowledge or delivery of evidence-based care, and poor social support are all associated with stigmatization and ultimately can prove harmful to patients and their clinicians, and the ability to deliver optimal care. Read the full article to learn more about raising awareness about stigma in lung cancer.

About the IASLC:

The International Association for the Study of Lung Cancer (IASLC) is the only global organization dedicated solely to the study of lung cancer and other thoracic malignancies. Founded in 1974, the association's membership includes nearly 9,000 lung cancer specialists across all disciplines in over 100 countries, forming a global network working together to conquer lung and thoracic cancers worldwide. The association also publishes the *Journal of Thoracic Oncology*, the primary educational and informational publication for topics relevant to the prevention, detection, diagnosis and treatment of all thoracic malignancies. Visit www.iaslc.org for more information.

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