Science Background Helps Charlotte, N.C.-area Patient with Lung Cancer Cope with Diagnosis

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

When John Doll’s doctor told him he had lung cancer, he was surprised but hardly daunted. His background in organic chemistry, biotechnology, and pharmaceuticals and his experience working on thousands of new drug patent applications at the U.S. Patent Office prepared him for the complexity of cancer care.

For many patients with cancer, understanding and pronouncing the multi-syllabic words used by doctors and pharmaceutical companies to name drugs can be daunting at best and a real barrier to understanding and complying with treatment recommendations at worst. For someone like Mr. Doll, however, his specific diagnosis “lung cancer with MET exon14 skipping mutation,” practically rolls off his tongue.

Mr. Doll was diagnosed in January 2019 and started pembrolizumab immunotherapy for one year, including three rounds of stereotactic body radiation. When this treatment plan was no longer effective, he was prescribed crizotinib, followed by capmatinib, which was specifically approved by the U.S. Food and Drug Administration for his specific genetic mutation (MET exon 14 skipping). After 2 months, capmatinib was determined to be ineffective, so Mr. Doll started chemotherapy with a “cocktail” of carboplatin, pemetrexed and pembrolizumab. For someone as active as the 72-year old North Carolina retiree, the excellent quality of life he has enjoyed while on therapy has been a major victory.

“I’m doing amazingly well—I still work out with weights, and I bike regularly.” Because of the many advances in lung cancer, Mr. Doll can work on his lifelong passion of rebuilding an 1967 Corvette, volunteering with a lung cancer patient advocacy group and spending time with his four grandchildren, including a set of 6-year-old twin girls he calls his ‘twin tornadoes.’

As part of his patient advocacy work, Mr. Doll follows new scientific developments within healthcare in general and within lung cancer specifically as a way to better understand his own disease but also to help other patients better understand theirs.
“Before some of the newer therapies were approved, patients with lung cancer might only live a year or so after diagnosis,” he said. “Now, it’s not uncommon to live for up to five years and more, and in that time, an even better therapy may come along that gives you a better chance to beat lung cancer.”

Uniting Separate Perspectives into One Story

So many patients with lung cancer have similar stories to that of John Doll, 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, Mr. Doll’s perspective leads off several presentations on recent research therapeutic advances. Data on immunotherapy agents alone and in combination, as well as on treatment-related adverse-event management, will be followed by a live Q&A.

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 attendees will learn about how a number of patient-led groups are driving research in a presentation by patient research advocates Ms. Janet Freeman-Daily and Ms. Ivy Elkins, and in the presentation by Ms. Jill Feldman that highlights 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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