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Omaha Patient Pays Forward the Hope He Was Given During Lung Cancer Journey

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

In December 2013, Omaha, Neb., resident Frank Sierawski came down with what he thought was a typical winter cold that included a nasty cough. He thought nothing of it but when it persisted into February, he finally sought care. February turned to April and May without a diagnosis. An x-ray was not suspicious and his doctor at the time thought he might have pneumonia. He was advised to see a pulmonologist, which took another four weeks. Then another test for asthma and a chest CT and that led to a bronchoscopy, which eventually located the source of his symptoms—a tumor in his lung. Yet, his doctor did not order a biopsy.

Mr. Sierawski shared his frustration with friends, one of whom worked at Mayo Clinic in Rochester, Minn.

The friend suggested a more in-depth diagnosis and in June, he received a CT scan, PET scan and bronchoscopy. These second-opinion tests revealed a lung tumor with additional sites of metastases.

“I suspect it progressed over a longer period of time and, while I did have a nasty cough, many people with lung cancer have told me they have no symptoms,” he said.

After a biopsy and a biomarker test, Mr. Sierawski learned he had stage IV non-small cell adenocarcinoma and his biomarker test came back showing an *ALK* mutation on July 4.

Mr. Sierawski was given targeted therapy because of the genetic mutation, and he was able to work during the entire period when he was undergoing first-line treatment. After developing brain metastases, meaning that his cancer eventually spread to his brain, his targeted therapy was changed in order to provide better action in the brain.

“I was lucky because the targeted therapy has fewer side effects relative to more traditional chemotherapies, and that allowed me to continue my daily routines,” Mr. Sierawski said. “One thing that I’ve never forgotten is that my doctor at the time was not afraid to push for a cure—that was the goal.” Mr. Sierawski underwent a lobectomy—the attempt at a cure that his doctor

pushed so hard for—to limit the opportunity for further oligometastatic (cancer that has spread to just a few sites) disease. Mr. Sierawski believes that this type of local consolidation therapy, while not a fit in all cases, can be a way to extend survival, particularly when paired with a targeted maintenance therapy. After showing no evidence of disease for over three years now, the hope given to Mr. Sierawski by his physician is now being paid forward to others who are impacted by lung cancer.

Mr. Sierawski gives back to his community, both locally and in the broader lung cancer community, by volunteering with the Omaha chapter of the American Lung Association as well as the national lung cancer patient advocacy group LUNGevity.

In his volunteer role, he talks to recently diagnosed patients with lung cancer about their concerns. “I talk to them about side effects of their medications, insurance coverage issues, and financial considerations,” he said, all of which are important considerations for patients, especially right after diagnosis.

He is also quick to highlight the advances in research and treatment of lung cancer that have unfolded since his diagnosis in 2014. “At that time,” Mr. Sierawski noted, “oligometastatic disease and local consolidation therapy were obscure concepts that would have been seen as operating outside of the mainstream. The introduction of numerous new therapies has opened up avenues and treatment options that are meaningfully changing outcomes for patients across the lung cancer spectrum.”

Uniting Separate Perspectives into One Story

So many patients with lung cancer have similar stories to that of Frank Sierawski, 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. Sierawski’s perspective opens the portion of the program discussing treatment for oligometastatic disease, including rationale for local consolidation therapy.

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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