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Former Soccer Referee Gains Time with Targeted Therapy, Acceptance with Meditation, and Empowerment with Advocacy

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

As a soccer referee for high school and college games in Irvine, Calif., A.J. Patel would regularly log three to four miles during each match. He was committed to fitness, followed a balanced, nutritious diet, and had no known risk factors connected with lung cancer. The 54-year old was a picture of fitness and health.

So, he was surprised when he began wheezing after refereeing one match. The wheezing turned into a constant throat clearing for seven months that attracted the attention and concern of his office mates at the large insurance company where he worked.

“I went to my primary care doctor, but he just dismissed it as nothing serious. He said that it would get better on its own,” he said.

But after his work colleagues stepped up their urging, he went to an ear, nose and throat specialist, who suspected allergies. That diagnosis didn't seem right to Mr. Patel either so he bounced around to some other doctors before he found one who performed a methodical review of his health and ordered a chest x-ray that discovered a small nodule in his lung. Still, the doctor did not seem concerned and told Mr. Patel that a six-month follow up was called for.

“I trusted the white coat,” Mr. Patel said, and in Spring of 2013, he went on a family vacation, not knowing what was in store. He woke up one morning during the vacation coughing up blood. Knowing that he could now not wait another six months for a follow up, he went back to the doctor and got another x-ray and CT scan. Those tests confirmed the existence of the nodule in his lung from the previous exam. He sought out a lung cancer specialist, who could provide more answers.

After a flurry of phone calls, Mr. Patel was able to get in to see an oncologist who specializes in lung cancer, and that doctor reported that Mr. Patel had lung cancer.

“I remember that the doctor seemed to be shocked that my case was so advanced. He was more emotional than I was!”

Unfortunately, Mr. Patel subsequently learned that he also had brain metastases, meaning that the cancer had spread to his brain, and that he would need surgery.

“I’m healthy; I have few symptoms. I take care of myself, and there is no family history of lung cancer, but now I’m being told I have stage IV lung cancer,” he recounted. He learned that he both a three-centimeter tumor in the left hemisphere of his brain and an adjacent to a four-centimeter tumor.

“I asked them if they had the right charts,” he said.

Transformation

What followed led to a transformational journey that started with neurosurgery and ended up with a 10-day meditation boot camp.

“I was lucky because I was among the one percent who met the criteria of patients with a *ROS1* mutation at the time for a new drug called crizotinib,” he said.

The medication helped him fend off the cancer and gave him time to heal from the debilitating effects of his subsequent brain surgery.

“Once you have cancer, it affects your life every day. It’s silent and deadly and it wears you away mentally, emotionally and physically,” Mr. Patel said. “It’s like waking up every day to a room with wallpaper that says ‘cancer’ on it.”

He underwent counseling and searched for answers in religion, finally coming in contact with a local wellness and meditation clinic that provided him with tools to help him cope.

“When you have cancer, even a positive scan is a source of anxiety—you wait for the scan, you get the results, and you feel better. But then you realize you still have cancer,” he said.

During the meditation boot camp, Mr. Patel woke at 4:30 a.m. each morning and meditated for 10 hours a day, with a five-minute break each hour.

“The first three days were grueling, and my back was killing me,” he said. “But after that, I felt great and learned how to deal with my anxiety about my cancer.” Mr. Patel is also sharing his meditation skills with other patients with cancer. He recently led a meditation group session of patients with lung cancer, who like him, were searching for answers.

Mr. Patel has also transformed his individual patient story into a perspective that is more focused on the lung cancer community as a whole. Aside from the meditation groups, he has participated in LUNGeivity and Lung Cancer Foundation of America advocacy events. He has been a U.S. Department of Defense consumer reviewer in the Lung Cancer Research Program.

He has also participated in a video series in which he shares his experiences with living with lung cancer as part of the Bristol Myers Squibb Survivorship Today series.

Uniting Separate Perspectives into One Story

So many patients with lung cancer have similar stories to that of A.J. Patel, 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. Patel's perspective opens the portion of the program in which challenging real-world cases are discussed by a panel of multidisciplinary experts.

Improved knowledge about genetic mutations and the immune system has led to improved treatments and an increased number of 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 research advocates are driving research in the 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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