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Navy Veteran Employs Survival Attitude to Help Other Patients with Lung Cancer

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

Aldie, Va., resident John Ryan lived and worked in nuclear submarines for a significant part of his Navy career, which ended with his retirement in 1992. Despite his ability to stay calm under pressure and the resilience that he demonstrated throughout his career, a stage IV adenocarcinoma lung cancer diagnosis in 2013 caught him off guard. Rather than feel unfortunate about his diagnosis, the 76-year-old attacked his condition with an assertiveness fitting of a former Navy man.

He sought second and third opinions, reaching out to noted oncologists, Dr. William Pao, at Vanderbilt University and Dr. Julie Brahmer, at Johns Hopkins. His persistence paid off when he was the 17th patient at Johns Hopkins Hospital selected for a phase III clinical trial testing a new immunotherapy, a class of drugs that were in their infancy at the time.

“Let’s face it, the cancer was winning, and there were not many options for me in 2013,” he said. “I had lost 50 pounds, and I was experiencing severe shoulder and arm pain after my first four cycles of chemo. Food tasted terrible and I had virtually no energy,” Ryan recalled.

But Ryan’s luck improved, and his health began to improve quickly. His tumor shrank to 65% of its original size by the end of 2013 and 83% by the end of 2014. His quality of life was restored, and he was able to participate in all the activities he enjoyed prior to his cancer diagnosis. Mr. Ryan continues to receive immunotherapy treatments and with 131st infusion, he began his eighth year of immunotherapy this week.

“I was able to attend three university graduations and two weddings,” he said proudly. Of high importance, he was able to support his daughter, who was going through her own battle with breast cancer.

“My experience with lung cancer and my survival despite the rough beginning has allowed me to convey to my daughter how to stay strong and positive and rise above the disease. Offering her ongoing encouragement to minimize the negative impact of the disease experience and offering sustained praise for her incredible personal resolve in confronting many difficult disease challenges has helped her to achieve her pathologic complete response.”

As a patient with cancer, Mr. Ryan still faces many challenges, including coping with the heightened risks during the COVID-19 pandemic.

Mr. Ryan believes he owes a debt of gratitude to the doctors who treated him, including Drs. Carter, Pao, and Brahmer, and he repays that by volunteering as a patient advocate, sitting on congressional directed review panels for lung cancer research.

Uniting Separate Perspectives into One Story

So many patients with lung cancer have similar stories to that of John Ryan, 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. Ryan's perspective opens the immunotherapy-focused session of the program, in which the nuances of using these therapies in various settings and how new biomarkers could improve therapeutic selection will be discussed.

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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