



Chris Martin
Vice President, Public Relations
CMartin@DavidJamesGroup.com | 630-670-2745

October 16, 2020

Changing Jobs Saved Florida Woman's Life

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

As a lifelong Pittsburgh area native, Melissa Crouse never dreamed of leaving the “Steel City.” She loved her job as a music teacher at a local middle school and was an avid Steelers fan.

“But every time I would visit my brother in Florida, he would try to convince me to move down there,” Ms. Crouse said. His persistence must have paid off because her instincts told her it was time to make the move.

“I applied for a few jobs at schools in the Fort Myers area, thinking that I probably wouldn't be considered,” she said.

Ms. Crouse was surprised to learn that not only was there a strong response to her resume, but she soon got several job offers, including one at the Cypress Lake Middle School. Before she could start, she had to take a physical, during which the doctor detected a spot on her upper left lung that turned out to be lung cancer.

“The move to Florida and that physical saved my life,” she said.

The diagnosis began a 15-year journey that has taken her through a range of lung cancer treatments and clinical trials, from chemotherapy and radiation to surgery and immunotherapy.

During the first phase of her treatment, she spent nearly three years on chemotherapy including participating a clinical trial. One day the school librarian told her about a news story that featured doctors from Massachusetts General Hospital in Boston, who were recruiting relatively young, otherwise healthy women who never smoked for a lung cancer clinical trial.

Ms. Crouse went from clinical trial to clinical trial. At Mass Gen in 2012, it was discovered that she had a *RET* mutation indicating that she would be a candidate for a targeted therapy for patients whose tumors express that genetic mutation. It wasn't until 2017 that a clinical trial targeting the *RET* mutation became available. Melissa enrolled in the trial in April, 2017. She made trips to New York once a month until the beginning of the pandemic. She was often accompanied by her sister, who lived in Philadelphia. The trial drug is now approved.

Once enrolled in a trial designed for patients with her tumor's genetic profile, her health improved and today she has no evidence of disease, although she does not consider herself free from cancer. Her experience from six clinical trials, conversations with dozens of oncologists, nurses, and other health care providers gave her keen insight to what patients with lung cancer endure to survive. She took that experience and turned it into something positive, starting the SW Florida/Ft Myers Lung Cancer Support Group that meets monthly, as well as contributing time and energy to LUNGeVity, an excellent lung cancer patient advocacy organization.

Now retired after 13 years from teaching music in Fort Myers, Ms. Crouse also serves as a consumer advocate reviewer on committees that serve pharmaceutical companies and government agencies.

"My local oncologist, who treats patients with most types of cancer, credits me with teaching him a lot about lung cancer," she said. "There is so much information for doctors to keep up on, it's helpful to have someone with my experience and perspective." Ms. Crouse provides feedback on communications materials and informed consent forms, too, encouraging pharmaceutical companies to make instructions easier to comprehend.

"After my diagnosis, I was in a daze and it took me a while to get my bearings," she said, making it difficult to read all the complex material about her disease and treatment.

In her volunteer work with her local support group and with LUNGeVity, Ms. Crouse speaks to people who have just received a lung cancer diagnosis. Her first advice is to make sure to get comprehensive biomarker testing done to determine if there is a targeted therapy that is right for you.

Having a positive attitude can be helpful.

"I've always felt like I should live my life the way I want and not to let cancer determine every step I take," she said.

Uniting Separate Perspectives into One Story

So many patients with lung cancer have similar stories to that of Melissa Crouse, 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. Crouse's perspective leads off several abstract presentations regarding lung cancer that is driven by rare oncogenic drivers, including a discussion of resistance to pralsetinib in patients with *RET* fusions and non-small cell lung cancer (the ARROW study). These presentations illustrate the importance of the comprehensive biomarker testing that Ms. Crouse stresses in her advice to other patients in order for optimal therapeutic selection.

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 panel discussion “What Research Patients Have Contributed,” with 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.

###

